

WHY A DEMENTIA DIAGNOSIS DOES NOT NEED TO BE A DEATH SENTENCE

KAREN LOVE and CYNTHIA HULING HUMMEL, DMIN

Laurie Scherrer was enjoying a successful career. She had a knack for easily picking up almost any computer program and for carrying projects through from conception to completion. In addition, she was a natural leader and enjoyed helping others grow to their full potential. Scherrer's life changed suddenly, though, when in 2011 she began experiencing difficulties with basic math and started repeating herself. Although she had always been a positive thinker and motivator, she became increasingly agitated by people and events. It was when Scherrer started getting lost driving in areas she knew well that her husband became very concerned. Thus began the process of trying to figure out what was happening to her. Scherrer was referred to four physicians and soldiered through 30 hours of neuropsychological tests and neuroimaging. After additional testing, a fifth referred physician informed Scherrer and her husband that she had early-onset Alzheimer's, confirming what her four other doctors were not comfortable diagnosing.

Astonishingly, Scherrer's diagnostic experience was not unique. According to an Alzheimer's Association study released in 2015, more than 50% of physicians do not tell their patients that they have dementia.¹

Many physicians are not comfortable delivering a diagnosis of dementia because they believe that little can be done as there are no medical cures. After being diagnosed, patients typically are told to get their affairs in order and return in six months for monitoring. Rarely do they receive information about how to live with and manage the symptoms of dementia, a chronic condition that will last the rest of their lives.

There are few support resources available to them as are accessible to people with other chronic conditions, such as stroke, heart disease or traumatic brain injury. People with dementia are left to figure out how to live with and manage this complex medical condition by themselves. Adding to the trauma, they face significant stigma and the prevalent societal doom-and-gloom narrative, all of which lead to a deteriorating state of learned helplessness, depression and isolation.

According to the World Health Organization's 2021 Global Status Report on the Public Health Response to Dementia, dementia is the leading cause of disability and dependency globally.² Despite its prominence in causing disability and dependency, many in the medical and scientific communities remain focused on finding a cure rather than on understanding the various symptoms to lessen the onset of disability and dependency and better support people and families living with dementia.

Two longitudinal, population-based studies, the Cache County Study in the United States and the IDEAL study in the United Kingdom, have yielded many insights about living with dementia. This and other research show that peer support and living proactively with healthy lifestyle habits, such as reducing stress, being physically and socially active, doing things that are fun, interesting and meaningful, getting restorative sleep and eating nutritiously, not only contribute to well-being but can actually help manage some of the symptoms of dementia. These low-cost, non-medical, strength-based interventions can be very effective in supporting abilities and fostering



Photo by Cynthia Huling Hummel

Cynthia Huling Hummel created a “memory bench” where she sets out reminders and items she’ll need for each day of the week. She has dementia, and these items provide cues to her daily schedule.

a sense of purpose that contributes to well-being. Despite these scientific findings and abundant anecdotal evidence, disabling status quo practices remain the norm.

Cynthia Huling Hummel, DMin, one of the co-authors of this article, is living with early-onset Alzheimer’s. Her upbringing oriented her to having a proactive and positive approach to how she lives. Huling Hummel is part of the small population of people living with dementia who inherently focus on strengths and betterment that have served them well while living with dementia. (Read Huling Hummel’s story where she shares her positive lifestyle strategies in the sidebar.) It’s been 10 years since Huling Hummel was first diagnosed with cognitive impairment. Has her proactive lifestyle limited symptom progression? It’s very likely. There is abundant research that attests to the positive effects to well-being from building resiliency when faced with adversity.³⁻⁷ Learning one has dementia triggers a natural grief response. People cycle through feelings of denial, anger, bargaining and depression. These feelings are common, and some illnesses progress rapidly, even with people’s best intentions to manage both their physical and emotional conditions. With so-

cial and emotional support, a person often can and does reach acceptance, which is a pathway to building perseverance and having a self-help attitude.

As shared in her story, Huling Hummel’s transitional step to move from “Why Me?” to “What’s Next?” is rarely discussed but is key to acknowledging and accepting a condition and gaining a

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sense of control over it. Building resilience and other proactive healthy lifestyle choices while living with early symptoms of dementia can be very beneficial. Physicians and their offices are usually the front door to information when diagnosing people with dementia and typically do not educate early about the benefits of having a positive mindset (e.g., focusing on finding the good in a situation as opposed to dwelling on the negative aspects) and a proactive approach (e.g., being actively engaged in one’s well-being rather

than relying on others) to help with managing the symptoms of dementia. Taking an active role in one's health, such as staying socially engaged, is empowering and spirit boosting and contributes to overall well-being.

Huling Hummel's doctor did not provide this education, but she follows her mother's belief that

in helping others one helps oneself. Also, she believes that thanking God for one's blessings instills a focus on positivity and proactivity. She cycled through the stages of grief and got to a state of acceptance. From there, she stopped focusing on her losses and instead started counting her blessings. This positive mindset shift caused all sorts of new

LIVING WITH DEMENTIA

In 2011, Cynthia Huling Hummel was diagnosed with amnesic mild cognitive impairment (aMCI) due to Alzheimer's disease. Today, Huling Hummel performs intermittent services as a retired pastor in addition to being an artist and advocate for those living with Alzheimer's or dementia. In her words below, Huling Hummel shares her strategies on how she has continued leading a fulfilling and productive life.

"Looking back, my cognitive abilities began to subtly change in 2003 when I was 49 years old. I was an ordained Presbyterian pastor serving a busy church in upstate New York. It started with me forgetting parishioners' names and what they had shared with me. I also began missing meetings and events. In 2007, I moved to a new parish and found that my cognitive challenges had come along with me. One day I could not find my way to the only cemetery in town where I had been multiple times — a grieving family was waiting there for me to bury their loved one.

My maternal grandmother, mother and uncle all had forms of dementia, so I was not surprised when I was diagnosed in 2011 with aMCI due to Alzheimer's disease. I spoke to the church's leadership team and decided to step down. Leaving the parish required moving out of the parish residence and getting set up elsewhere. I really missed being a pastor and was angry about the situation and with God. It took me a while to move from "Why Me?" to "What's Next?"

I have a new ministry now: helping people living with dementia and others on this journey. My mission has led me to become a national speaker, advocate and advisor while also having served on the National Alzheimer's Project Act's esteemed advisory council to provide my first-person perspective about living with dementia.

Today, I also sing and play guitar in a band and enjoy covering services for pastors when other

duties arise and they need to be away from their parishes. In addition, I get great enjoyment taking classes at Elmira College — 40 to date — and doing art projects. To my joy and amazement, one of my art endeavors, my mask series, has been exhibited internationally. When I learned that physical exercise was important to cognition, I made it a priority to get to the pool three to four times a week and have found that an early morning swim energizes me. In good weather, I enjoy kayaking the local waters. I am busy doing things that are interesting, fun and meaningful. Moreover, I stay socially engaged and active, maintain close personal relationships, am mindful about getting restorative sleep and eating nutritiously and careful to keep stress to a minimum. I am living my life positively and know that I don't get to pick and choose the difficulties life brings my way, but that I can decide how I will react to the challenges.

To help me on a day-to-day basis, I have developed strategies that I have found effective. These include using both a paper and an electronic calendar and laying out my week on what I call my 'memory bench' (think church pew). The latter involves setting aside seven piles, one for each day of the week, so I can visualize what I am going to be doing each day. Additionally, I ask my health care providers for extra reminders about upcoming appointments, and I will also put a paper reminder on the middle of the floor so I don't forget something important. I live alone, which makes it even more imperative to have circles of support in place. Overall, I remind myself of the following: to not focus on what I can't do, but to focus on how I can still make a difference. Through my work, I hope I can encourage others facing a similar diagnosis to do the same throughout whatever obstacles they may face."

possibilities to open up for her.

The medical community embraces psychosocial-spiritual aids, including peer support; mindfulness and deep breathing training; and psychotherapy, among further assistance for other chronic conditions. Yet, unaccountably, this is not yet done for dementia. Imagine the improved quality of life people with dementia and their care partners could experience with these basic supports.

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NOTES

1. "New Alzheimer's Association Report Finds Less Than Half of People With Alzheimer's Disease Say They Were Told the Diagnosis," Alzheimer's Association, [https://www.alz.org/news/2015/new-alzheimer_s-association-report-finds-less-\(4\)](https://www.alz.org/news/2015/new-alzheimer_s-association-report-finds-less-(4)).
2. "Global Status Report on the Public Health Response to Dementia," World Health Organization, September 1, 2021, <https://www.who.int/publications/i/item/9789240033245>.
3. T. D. Cosco, K. Howse, and C. Brayne, "Healthy Ageing, Resilience and Wellbeing," *Epidemiology and Psychiatric Sciences* 26, no. 6 (December 2017): 579-583, <https://doi.org/10.1017/S2045796017000324>.
4. Eve Ekman and Emiliana Simon-Thomas, "Teaching the Science of Human Flourishing, Unlocking Connection, Positivity, and Resilience for the Greater Good," *Global Advances in Health and Medicine* 10 (June 2021): 1-11, <https://doi.org/10.1177/21649561211023097>.
5. "Well-Being Concepts," Centers for Disease Control and Prevention, <https://www.cdc.gov/hrqol/wellbeing.htm>.
6. "Positive Emotions and Your Health," NIH News in Health, August 2015, <https://newsinhealth.nih.gov/2015/08/positive-emotions-your-health>.
7. Nansook Park et al., "Positive Psychology and Physical Health: Research and Applications," *American Journal of Lifestyle Medicine* 10, no. 3 (September 2014): 200-206, <https://doi.org/10.1177/1559827614550277>.

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