

Testimony in Support of S.302
House Human Services Committee
April 25, 2024

Introduction

We moved to Vermont from Rochester, NY, ten years ago today. Two and a half years ago, we made a firm commitment to stay here by purchasing a house in St. Johnsbury where we now live. We love Vermont!

About four years ago, Darryll was diagnosed with Mild Cognitive Impairment (MCI), which eventually led to a diagnosis of Alzheimer's Disease.

The Importance of Educating Health Providers

We were very lucky. Darryll's daughter, Megan, happens to be a registered nurse at Dartmouth-Hitchcock Medical Center (DHMC). When Barbara told Megan she had noticed some changes in Darryll's memory and cognitive function, Megan urged her to get a referral to a neurologist to administer a "baseline memory test." That appointment (with a nurse practitioner) resulted in the MCI diagnosis, which is the typical first step on the Alzheimer's diagnosis journey. In the caregiver support groups she attends, Barbara has heard many stories from caregivers who got stuck at this stage of the process, unaware of the additional testing their loved one should have. Fortunately, we thought it important to follow up with a neurologist.

Here, we were lucky again. We happened to have a close friend who, through her own journey with her late husband's dementia, knew the former head of Neurology at DHMC and – on our behalf – asked him whom he would recommend we see there. Relatively quickly (perhaps because we referenced the former director?), we got an appointment with a very skilled and experienced neurologist at DHMC.

Another lucky break came, not from that neurologist, but from Darryll's primary care physician who told us about the Bennington Memory Clinic. Darryll quickly applied to enroll in a clinical trial for Eli Lilly's drug, donanemab (likely the next in line for FDA approval). As part of the screening process, Darryll had two PET scans – one that detects beta-amyloid plaque and another that detects the Tau protein. To be accepted into the trial, Darryll had to have a certain level of both. So when we got word that he was accepted into the study, we knew he definitely had Alzheimer's. Many people do not get this definitive diagnosis, because PET scans are quite costly.

We believe:

1. Health providers can play an important role in early detection of dementia by listening with trained ears for clues from patients and/or their family-members that a referral to a neurologist for testing is warranted.
2. Neurologists who make an MCI or dementia diagnosis should offer patients and their care partners a guide to resources to help them learn about and navigate the disease's progression.
3. While not everyone will opt to participate in clinical trials, we believe health providers should alert patients to these opportunities as soon as they make an MCI diagnosis. Many trials have cutoffs for age and/or progression of the disease, so the sooner patients can apply, the more likely they are to qualify.

The Benefits of Early Detection

Early detection of Darryll's Alzheimer's has allowed us to:

- Enroll in the clinical drug trial

- Learn about the disease before we were overwhelmed by it. In particular, Barbara has been able to take a caregiver's class through UVM, watch videos and listen to podcasts on caregiving – and vital self-care – techniques, and read numerous books and articles about caregiving. All of this activity will maximize her ability to take care of Darryll in their home. **If Darryll were further along in his disease, Barbara would not have nearly the amount of time or flexibility to take advantage of these opportunities to develop her caregiving skills/knowledge, as well as techniques to maintain her own well-being.**
- Attend support groups to help us anticipate and prepare for what's ahead. **Again, because Darryll was diagnosed early, Barbara has had the freedom from major care responsibilities to be able to attend these sessions.**
- Develop and strengthen personal support teams among friends and family
- Discuss and document Darryll's advance care planning while he is still able to express his wishes
- Prepare financially for the costs ahead
- Proactively surrender Darryll's driver's license before a tragedy could occur
- Be more aware of how precious our time together is, planning trips and other "bucket list" experiences while Darryll is still able to enjoy them.

Raising Public Awareness and Destigmatizing Dementia

We are deeply committed to destigmatizing Alzheimer's and other dementias. From the minute he was diagnosed, Darryll has been completely open about his diagnosis. He even contacted our local paper to ask them to do an interview with him about Alzheimer's – they obliged with a cover story, complete with photo! Everyone in St. Johnsbury knows that Darryll has Alzheimer's!

We have been active advocates with the Alzheimer's Association Vermont Chapter – testifying on important legislation like this one, meeting with state legislators and the lieutenant governor, serving as Alzheimer's Ambassadors to Bernie Sanders' office, and attending rallies in Vermont, Boston, and Washington DC. Last year, the Alzheimer's Association enabled us to create a 5-minute video – titled "Embracing Alzheimer's – about our journey with Alzheimer's which we now are taking "on the road" across Vermont to raise awareness and decrease stigma.