

Tara Graham, Executive Director/Administrator, The Arbors at Shelburne
Testimony to the House Human Services Committee, 02/12/15

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My name is Tara Graham. I am proud to be licensed both as a clinical social worker and as a nursing home administrator. I have been working in the field of geriatrics since early 2011 and before then had worked for over 10 years serving Vermont children and families. I currently serve on the Governor's Commission on Alzheimer's and Related Dementias and am an Alzheimer's Association Ambassador to Senator Sanders.

I work for Benchmark Senior Living which owns and operates The Arbors at Shelburne, a Senior Living Community that maintains both a Residential Care Home License and a Nursing Home License and has been providing specialized memory care with a capacity of 64 residents at any given time and their families for over 26 years.

I began as the Director of Resident and Family Services and then worked towards my nursing home licensure so that I could move into the Executive Director position, which I did in December 2013.

I was asked by your Chair, Representative Ann Pugh to share with you what it is that we do at The Arbors and what we have come to know as the experiences of people impacted by Dementia. My knowledge is based on having served over 259 residents and their families as well as collaborating and partnering with the many community agencies who attempt to adequately serve this vulnerable population. I hope to honor and do justice to their lived experiences through this testimony.

A little bit about our approach and what we do at The Arbors:

Most of our residents have exhausted alternative living arrangements. Many come from home where they had in place 24 x 7 private duty caregivers in place; some have been cared for by family members (often whose own health has become compromised) and some from other Residential Care Homes where they have assessed the resident as "beyond their level of care." Our community is also entirely private pay, which is only offset by having procured a Long Term Care Health Insurance Policy. What I have learned since entering this field, is that Vermont has not been an exception – most memory care communities that excel at what they provide are private pay. Most Vermonters who experience Dementia would not be able to pay out of pocket for the cost of care in a Specialized Residential Care Home or Nursing Home.

We strive to provide a resident focused and family centered experience. We intentionally provide outreach and services to family members of residents and attempt to engage them in our community at a level that feels meaningful to them.

In a very simplistic way, and what I encourage every associate who works at the Arbors to do, is to provide joy to our residents. If someone is distressed, comfort them. And while this sounds very easy and straightforward, for family members who are in the midst of anticipatory grief and loss over the person who they have loved and who has been so familiar to them; the ability to suspend your history with the person before you and offer joy unencumbered proves to be nearly impossible. It takes support, it takes strength and it quite literally, takes a village.

The residents we serve have all had very colorful and successful lives; those who are in earlier stages express frustration at the changes they are somewhat aware of. For those whose disease has progressed their families describe them as “tragically and slowly losing their words, their minds, their intellect and the relationships that they once held most precious.”

We watch time and time again, the emotional and financial strain left to caregivers –whether they are spouses, adult children, court appointed guardians, relatives or friends.

Some of our residents remain in our community through the end of their lives, others are there for some time and we help them to transition back to their homes with a better support plan in place, and still others exhaust their resources and move to a skilled nursing facility or a residential care home that accepts Medicaid payment from the state.

What we know:

We know that the course of dementia is as varied as the individuals who experience it. We know that there is no way to predict how long someone may live with the disease. We know that people who are living with dementia can still experience joy, connection and love. We know that by validating their emotions and their feelings that they are able to experience less fear. We know that when a person with Alzheimer’s or Dementia is aggressive, it is because they felt scared or threatened. This affords providers an opportunity to learn better how to respond and approach residents.

We also know that the stories of residents who planned to live apart from their families is few and far between. In my time at The Arbors, there is a single resident who I can confidently state steered her own boat –she told her family she needed to live in a safe and specialized community. She made these plans and had the forethought to prepare in this manner. More often, family members are left struggling with what to do and when – how to assess and access services and supports as they navigate this very daunting isolating road. One tragic scenario is watching married couples who have lived together upwards of 65 years live apart for the first time. No one prepares or plans to live away from the people that they love most in the world. It just isn’t what we spend our time thinking about or planning for.

The only 2 circumstances that I can think of where this happens is:

- 1) in the case of having a loved one incarcerated or
- 2) in the case of a loved ones’ advancing dementia.

At some point, people with dementia may exhaust home-based resources because caring for someone who is living with dementia is not a one-person job. It requires teams and teams of people. And we have to acknowledge as a state that there are many different constellations of family and community and many, many people live alone or in very remote and rural settings. These factors contribute to the vulnerability of seniors living with dementia. And while I wholeheartedly support the theory and philosophy of initiatives and programs aimed to keep people in their homes as long as they wish, in the context of dementia this is often not safe or practical. And I have often thought that keeping this philosophy at the center of our aging discussion inadvertently contributes to family caregivers suffering tremendous guilt where they might have felt support if offered choices. That is, if choices existed.

As I prepared for today, I reached out to some of our family members, past and present and asked what they thought would be most important to share with you today. What follows is a list of their priorities:

- More facilities dedicated to memory care – a growing need and not enough places throughout the state.
- Paid family time extended so that people caring for their aging parents can also meet the needs of their own children.
- More support/guidance for families caring for a person with dementia at home.
- Improved funding -- even with help from LTC insurance, the costs are prohibitive in the long run.
- More qualified Alzheimer's facilities.
- More affordable caregiver support.
- Enhanced workforce capacity so that we can bring services to people with Dementia. I.e. home based physicians and dentists.
- Insurances should provide some compensation for caregiver support – not just for nursing – certainly would be beneficial for the insurance company to keep the patient at home as long as possible instead of paying for institutional care.
- Affordable and accessible care: Many families do not have the funds to help their loved one. In addition, the cost of long - term care insurance is very expensive and is not indefinite in term, making family members have to potentially move their family member. Moving a person with dementia / Alzheimer's is not easy as you do not want to impact their routine and cause any upset.
- Task Force to determine how to better care for our seniors: The nursing home model needs to be revamped. Memory care centers need to be able to accept Medicaid as payment. Most families in the United States cannot afford the cost of a good facility dedicated to memory care. A son or daughter should never be in the position of 'settling' on a facility because they cannot afford the best.
- Funding for research: This disease that has been around for decades; there needs to be more funding allocated and research done at the state and federal level to make advances for a most debilitating disease that affects all members of the family.
- We need the state/federal government to play a much larger role in the oversight of nursing homes making sure all residents are treated with dignity, respect and receive excellent care.
- We should provide Incentives to assisted living facilities and residential care homes to allow the transition to a memory care neighborhood and accept Medicaid as payment so that all seniors can receive the best care and attention.
- We need increased funding for clinical trials / studies that will bring new medications to the forefront that target the cause of Alzheimer's disease.
- We need to create a public LTC insurance program for Vermont.

While resources are available in some parts of the state for those living with Dementia, such as Adult Day programs, in home assistance, etc. for the majority of families seeking support, these are out of reach financially. Even though many services do exist, there remains a disconnect between service providers knowing about available resources etc... Having come from children's mental health, I had thought then that the efforts were saturated and duplicative. With regards to aging, we are in a unique time in that while there hasn't been much done; this also means we haven't done much wrong. I do believe that seniors, especially those with dementia are entitled to a coordinated services plan, much in the way that a youth would be entitled to under Act 264. If there were collaborations happening locally between the areas Agencies on Aging, dementia care providers, AHS/DAIL, and medical providers that at a community level, more people would understand the emergent need for resources and coordination of care and funding to support these efforts.

Most awareness campaigns focus on prevention and raising awareness about the impact of the disease and need for research. This is important, but our state has to raise the level of consciousness about the experience of having this disease and loving someone with this disease. We need to have a campaign that acknowledges and educates the community about this disease and the many, many layers of it – good, bad and indifferent. Because living with the disease doesn't have to be all bad.

Loving people with Dementia has opened my heart and made me a better person in this world. It has taught me to be still and thoughtful and to cherish time with family and friends, and yes, to plan, plan, plan for what is possible in my future.

There is a wonderful, endearing side to Alzheimer's care, in that residents and families expose their own vulnerabilities and often connect in the most beautiful of ways. It is also comical at times, when loved ones have lost all their inhibitions or experience absolutely everything as new. As one family member shared, "having dementia isn't that bad. It's like mom gets a new outfit everyday. She loves that?"

What I would like to see for Vermont:

While I support the Alzheimer's Association financially and with volunteer efforts, the idea of eradicating Dementia seems far too enormous for me to conceptualize. I spend most of my time hoping and wishing for a day when people living with Dementia could go to the hospital and not be asked to verify their name and date of birth; where physicians understand how to have the very difficult but realistic conversation about diagnosis, risks and planning when it becomes too dangerous for someone living with dementia to be operate a vehicle; where people understood that Dementia is a disease and not something to be ashamed of; where learning about Dementia and grief and loss was part of all public school curriculums, where anyone seeking to place their loved one in an out of home setting has access to options and the very best trained and informed care providers; where law enforcement officers and first responders are able to readily tailor their approach because they understand someone has dementia; where no one approaches a person with dementia by saying "Stop" or "no"; where public bathrooms are designed so that a care provider could assist their loved one in public; where there would be an opportunity for a care provider to give real data and information about a patients to a physician and be taken seriously; where caregivers did not experience a rapid decline in their health as a result of caring for another person.

While Alzheimer's has been disproportionately funded and paid less attention to, I think that our aging population has also been overlooked. They are nearing the end of their lives. The interventions we put in place are essentially to help them live with dignity and with as much joy as possible and to alleviate the stressors experienced by caregivers; but it is not as appealing in terms of financial investments and outcomes. Not many foundations or philanthropists identify this issue as pressing. Not many people want to fund Alzheimer's Best practice or care. But perhaps if people understood that caring for our seniors was a reflection of how we care for the most vulnerable people in our society, then they might start to feel differently. We need to re-frame the outcomes so that we are not so future-oriented; but looking to improve the lived experiences of individuals living with an awful disease.

What can a Legislator do?

- Recognize Alzheimer's as the threat to public health and well being that it is.
- Know to connect your constituents with The Alzheimer's Association or their local area Agency on Aging.

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- When you are considering any legislation that impacts people ages 45 and over; think about the potential and unintended implications of that legislation on a person with dementia and the family members who shouldering the responsibility to care for that person.
- Enhance early detection, screening and diagnosis across the Health Care System.
- Request that the Cognitive and Caregiver module be used in the 2016 Behavioral Risk Factor Surveillance System so that we are able to gather necessary data to secure funding and plan accordingly in years to come.
- Support legislation or efforts to educate the public and leadership in our state about the prevalence of Alzheimer's Disease and Related Dementias and increase support and resources for the growing population.
- Support early diagnosis and screening efforts so that people when they are still able to, can participate in decision making and get much needed support.
- Support the work of the Governors Commission.
- Commit to providing increased funding and resources to the Statewide Dementia Respite Caregiver Program. It is family caregivers who carry the greatest burden of this disease.

In closing, I think Abraham Lincoln, who's birthday is today, said it best when he said "and in the end, it's not the years in your life that count; it's the life in your years."

I hope that you will join me and other Vermonters who would like there to be more quality to the lives of people living with dementia, as well as those who care for them.

Thank you for your time.