

Written Testimony in Support of HB 446

Dementia Services and Brain Health Program and Clinical Toolkit

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Chair Bagnall and members of the Committee,

My name is Joann Donnellan. I am a resident of Silver Spring, and I grew up in Beltsville, Maryland, where my parents lived for more than 55 years. I come from a medical family — my father was a dentist in Hyattsville, and my mom was a nurse at GW. I also have a background in health policy and advocacy.

Even with that experience and access to care, navigating my mom's dementia was incredibly challenging. I am here today to respectfully urge you to support HB 446 – Dementia Services and Brain Health Program and Clinical Toolkit.

My mom, Beatrice, lived with dementia for 17 years. She was diagnosed early at 66 years old in 1997 and remained at home until she passed away in 2014. My family and I were her primary caregivers throughout her illness, along with hiring weekly caregivers to help.

As a former nurse, my mom understood health care, yet when she became the patient, she faced a system that was not always prepared to support someone living with dementia. Through it all, she never complained. She truly was the best patient, even as the disease progressed.

When we first noticed changes in my mother, we visited multiple doctors searching for answers before finally receiving specialized care through the Memory and Alzheimer's Treatment Center at Johns Hopkins because my friend worked at the hospital. We were also fortunate to have an excellent geriatrician who closely monitored her overall health. Despite receiving strong medical care, our family still struggled to find guidance about dementia-specific resources and support services closer to home.

Traveling regularly from Beltsville to Baltimore or Washington, DC, for services was difficult and emotionally and physically draining. Because support options were fragmented, we ultimately created our own system of care. With the help of caregivers, we built what we often called a small senior center in our home, creating daily activities and engagement opportunities so my mother could maintain dignity, connection, and quality of life for as long as possible.

One of our most difficult experiences occurred in 2010 when my mom suffered a serious fall and broke her femur, requiring surgery, hospitalization, and a stay in a rehab center. While the hospital staff worked hard to care for her medically, many were not trained to care for someone living with dementia. I found myself explaining her condition repeatedly, helping staff understand why she could not follow instructions like using a call button or remaining still with medical equipment.

At one point, the staff became frustrated because my mom repeatedly pulled out her IV. She did not understand what the IV was or why it was there. I asked whether it could be wrapped or covered so she would not see it and be tempted to remove it. When that never happened, I used my running shirt to cover and help secure it myself. The night before her surgery, I stayed in the hospital bed with her, sleeping in a chair by her bed, holding her arm to prevent her from pulling the IV out again.

My mom also did not understand that she had broken her leg, that she needed surgery, or that she could not safely get out of bed afterward without assistance. My father and I rotated staying at the hospital in her room because we were afraid she would try to get up and fall again. It was exhausting and overwhelming, and I later learned some supports could have helped us if someone had simply connected us to them.

Once a hospital or physician knows a patient has dementia, the entire approach to care should change. There should be an immediate conversation about safety planning, available resources, caregiver support, and coordinated care. Families should not have to discover these supports on their own during moments of crisis.

HB 446 helps make that shift possible. By strengthening provider education, improving early detection, and creating coordinated dementia services across Maryland, this bill will help families receive guidance sooner, improve patient safety, and reduce the overwhelming burden placed on caregivers.

Families should not have to build their own dementia care systems just to keep their loved ones safe and supported. I believe this Clinical Toolkit for Dementia Care will be a gamechanger for families and patients, giving health care providers practical, evidence-based resources for early detection, diagnosis, and care planning.

In honor of my mom, Beatrice, and the thousands of Maryland families walking this journey, I respectfully urge you to support HB 446.

Thank you for your time and consideration.