

# Testimony in support of SB 290 and HB 5455

---

**Pamela Atwood, MA, CDP, Director of Dementia Care Services at Hebrew HealthCare, Inc.;**  
**member of State Legislative Task Force on Alzheimer's Disease 2013**

Good morning Senator Flexer, Representative Serra, and distinguished members of the Aging Committee. I am pleased to testify today in support of SB 290, An Act Concerning Patient-Designated Caregivers and Proposed bill 5455, An Act Concerning Caregivers.

I'm Pamela Atwood, and I'm a gerontologist and a Certified Dementia Practitioner. I have worked in the field of aging for 25 years. I have always been passionate about caring for people with Alzheimer's and related diseases because three kinds run in my family – this includes younger onset Alzheimer's. My cousin was diagnosed last year at the age of 57.

In the 1990s, my parents were here to testify in support of the Alzheimer's Respite program. Some of their testimony shared insight into the stresses of caring for my grandmother who struggled with Alzheimer's disease. Back then, doctors only spoke with families, and often we considered "Should we tell the person with cognitive impairment about their diagnosis?" The Patient-Self-Determination Act of 1990 somehow didn't seem to apply to elders with dementia. But as we learned more about cognitive impairments and a person's ability to communicate their choices and preferences we've made it important for them to be involved in their care decisions in partnership with family caregivers. But then came HIPAA.

The Health Insurance Portability and Accountability Act has been important to protect privacy of health information, but has been a pendulum swing in the other direction. Often it seems as if no one who "needs to know" can get information from health care providers. This is not the fault of doctors and nurses, but we are often unsure of WHO is the "NEEDS TO KNOW" person. These bills are an effort to bring the pendulum back to center.

As advocates from AARP, the Alzheimer's Association and other organizations will tell you, caregivers provide billions of hours of care annually at a value of hundreds of billions of dollars. In fact, in 2012, caregivers provided service to their family members at a total estimated value of \$216 billion; that's more than Medicare and Medicaid combined for that year (\$142 billion). It is vital to support this essential "partner" in our US health care system. When I served on the 2013 Legislative Task Force on Alzheimer's, we supported several initiatives to ensure quality care and support for individuals and their caregivers.

The measures in the bills in front of the Committee today are simply an attempt to eliminate the inconsistent application of HIPAA while ensuring adequate communication with the people who support those at risk for failure in the community – especially people with

cognitive impairments and frail elders. They don't take away any rights, or risk privacy protections. In fact, these bills would formalize best practices which are conducted in many health care institutions across the state.

My 57 year old cousin, Pat, looks like any other middle-aged female. She is well-educated, a real estate professional (now former real estate professional), and volunteers with the Special Olympics in her community. If she becomes sick and goes to the emergency room, people may not think that she needs a caregiver. In fact, she might put down her mother as her emergency contact. But Auntie Elaine died in November of 2013. Pat doesn't remember that. Her sister in law would arrive in the emergency room, and might be denied access to health information because she's not "next of kin." But if you asked Pat who helps her at home, she would tell you "Cumalee" her sister in law.

Cumalee truly has a need to know. If there is a change to Pat's medications, or a new medication, even a simple antibiotic, my cousin would not be able to understand the directions given by the medical staff -- although they'd be hard-pressed to think that -- Pat looks like you and me, and in the moment she might understand directions, maybe even repeat them back. But because of her damaged hippocampus and frontal lobes, she wouldn't remember those directions by the time she reached home.

Caregivers need to be contacted and kept up to date. They need to have instruction on how to implement the interventions and medications and follow up care that people have. If we really want to reduce re-hospitalization rates, reduce health care costs, and improve compliance with care recommendations, we need to ensure that the right people have access to that information and instruction. We need to support caregivers as vital partners in our health care system.

I ask your support of SB 290 and HB 5455 because I believe it is common sense to have a caregiver listed in medical records and to ensure that people with health care issues should be asked to designate a caregiver.

Thank you.