

**STATEMENT OF ANN BOWERS
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to

**SENATE SPECIAL COMMITTEE ON AGING
“The Future of Medicare: Recognizing the Need for Chronic Care Coordination:**

MAY 9, 2007

Good afternoon Senator Lincoln and distinguished members of the Committee. It is an honor to be here. My name is Ann Bowers and I represent one of the millions of family caregivers who struggle daily to confront the challenges of Alzheimer’s disease. I thank you Senator Lincoln for introducing the *Geriatric Assessment and Chronic Care Coordination Act of 2007*. I urge Congress to pass this bill as quickly as possible.

My ex-husband Jay Sweatman ushered in the new millennium as a 50 year-old divorced man with an MBA, two loving, preteen daughters and no family history of Alzheimer’s. He maintained active joint custody of his girls, owned a mortgage and escrow company and traveled frequently in volunteer positions on state and national boards in his industry. Within fourteen months of that milestone birthday, everything came crashing down. Repeated financial mistakes, misplaced money and overlooked details drove his business into the ground. After his business failed, he took and lost a succession of jobs – the last of which was as a stock boy at Sam’s Club Warehouse. In the middle of this we decided to end our marriage.

When I realized that this college graduate with an advanced degree in finance could not hold a job at Sam’s Club, I became concerned enough to move him from Albuquerque to Denver so he could be with me and the girls. We had been close since the divorce and I was growing increasingly concerned about his abilities. By this point, he frequently struggled to find words while speaking and was having difficulty carrying on a coherent conversation. It was apparent that he had a medical problem and help was sought. After four months of exhaustive neurological testing, a diagnosis of probable Alzheimer’s disease was made in March 2002. The neurologist handed me the phone number of the local Alzheimer’s Association chapter before we left his office that day and suggested that we get in touch with them to find out what services were available and where I could find help for Jay, me and our daughters.

That single gesture remains to this day one of the best things that has happened to our family throughout this journey. The Alzheimer’s Association in Denver was extremely proactive. They made sure I knew about day care and had an idea of what services might be available. They referred me to 24-hour telephone help and online bulletin boards where I could always find someone to talk to who understood what I was going through that day.

Finding help for Jay and a way to pay for services was an all-consuming task. Unemployment and financial mismanagement had left Jay with no resources or income. He was admitted in April 2002 to the Colorado Indigent Care Program to help cover his medical expenses. In May 2002 he applied for Social Security Disability Income but was told he did not qualify because he did not appear to need help and he was under age 60. The following month his lack of income

and resources qualified him for Colorado's Adult Needy Disabled program, which gave him \$250 month against any future Social Security benefits, as well as food stamps.

During this time Jay remained in an apartment across the street from our home. The children spent two or three nights a week with him and Jay felt this independence and contact with his daughters was critical to his well being. However by the winter of 2002 it was increasingly apparent that he could no longer reliably keep house, cook or groom himself regularly. In early 2003 Jay was finally approved for Social Security Disability benefits. He was also approved for in-home personal assistance. Unfortunately, by the time services were authorized, he was no longer able to live independently. Late that winter he moved to a personal care boarding home.

In the midst of trying to keep our heads above water and get Jay the help he needed, it never occurred to me to closely monitor his medication. After all, he had always been totally self sufficient. I had no idea that due to his impaired judgment, he was hoarding the medication that kept his other health problems – glaucoma and depression – under control. It was not until he tried to explain that something was wrong with his eyes that I learned he had stopped taking his regular medications. I realized he was losing vision from the sides – classic exacerbation of his glaucoma symptoms but ones I had never thought to monitor because I thought he was taking his medications as usual. A thorough search of his apartment confirmed that the pills I thought he was taking faithfully had been organized into neat piles in a dresser drawer. From that point on, every health problem quickly became a crisis. Jay's untreated glaucoma required extensive testing and we briefly considered surgery. He lost most of his sight in one eye. Frustration coupled with lack of medication for chronic depression led to threats of suicide. He had to be hospitalized just so we could get him on an adequate drug regimen and determine what he truly could and could not do on his own.

Hindsight is 20/20. We didn't know it at the time but we needed one person advocating for us and providing ongoing support regarding a plan of care for Jay, in coordination with all of his doctors and agencies that were providing care. Instead I tried to solve all of the problems myself, guessing what specialist he might need next and which condition to manage on any given day. There has to be a better system. The *Chronic Care Coordination Act* will prevent other caregivers from having to face the challenges my family did.

Maintaining Jay's health was only part of the struggle. Multiple wandering incidents landed Jay in the hospital again for medical re-evaluation. The assessment from the doctors at that point was that it was time to move him to an assisted living facility. After three months in assisted living, he became aggressive and physical and we were told to move him to a full service nursing facility specializing in Alzheimer's disease. Each of these moves required two to three weeks of full time searching by me to find available beds in appropriate facilities. "First choice" was never a consideration – simply finding an open bed available for a male patient was the biggest hurdle. We were thrilled to eventually secure a bed in an older facility that could provide the care he needed.

All of the moving from setting to setting was extremely hard on Jay, not to mention stressful for me and the girls. Having access to a care coordination benefit would have provided us with critical non-medical care, including managing transitions between care settings and offering

guidance on whether particular environments would work for Jay. Had a comprehensive geriatric assessment been completed, we could have properly evaluated Jay's cognition, needs and functional status on an ongoing basis to preserve his independence and ability to remain in the personal care boarding home.

Jay is now 57. He lives in a nursing home in Denver where he no longer recognizes me, his daughters or friends. I have taken on the added challenge of managing his care long distance, having moved to Arkansas in 2005 so that my daughters could be closer to my extended family. I work full time as a mortgage broker and serve as Jay's guardian. I'm in charge of all medical decisions related to his care because Jay does not have any other family members who are able to take on this responsibility. I speak weekly with the doctors and nurses at Jay's nursing home and visit as often as possible. It's not an ideal situation but it is the best we can do for now. I chose to tell my story in the hope that Congress will improve Medicare to bring down the costs of care for individuals with chronic conditions and increase the quality of healthcare provided. A critical first step is passing the *Geriatric Assessment and Chronic Care Coordination Act*. Families across the country, including those taking care of the 56,000 Arkansans living with Alzheimer's, cannot wait any longer for this kind of help. Thank you.