

Ian MacDonald  
North Central Regional Director  
Alzheimer's Association CT Chapter

Written testimony against further cuts to the Alzheimer's Respite Grant, and reduction to the agency's operating funds.

My name is Ian MacDonald. I am the North Central Regional Director for the Alzheimer's Association Connecticut Chapter. I am here today to voice my concerns regarding further cuts to the Alzheimer's Respite Grant, as well as cuts to the agency's operating funds. In my job, I interact with hundreds of caregivers, their extended families, and people with dementia. It is my great honor to work for this association, but there are many nights where I lay awake and wonder:

I wonder if the forty-six year old man in my early stage support group is going to sleep okay, or if he will wake up and wander. I wonder about his wife; if she leaves early from work again to care for her husband, will she lose her job?

On a daily basis, I speak to former leaders of industry, project managers, bankers, lawyers, neurologists – all cut down by this terrible disease. I listen to spouses, partners, daughters and sons who state, with tears in their eyes, that they did not sign up for this; a life of constant worry, struggle – a life of anger and frustration. I often wonder if I should comfort them. Tell them that it will be okay. But I can't. There is no cure for this disease. It robs families of their whole life. Friends no longer come out to visit, family's fight with each other, and a lifetimes worth of savings can be wiped away in a few, short years.

I am not here to say that the Alzheimer's Respite Grant, even if fully-funded, will solve these issues, but it is something. It helped a woman named Esther, whose husband was diagnosed with younger onset at age 56. It gave her some time to care for her mother, who had been diagnosed with cancer. It gave her some piece of mind knowing that her husband would be safe and cared for. It offered some relief financially, as she was struggling to provide for her family on her income alone.

I have no doubts that some of the testimony you hear today will talk about caregiver stress. They may talk about depression and anxiety, a weakened immune system, weight gain, the list goes on. They may mention that 30% of caregivers die before those they are caring for. I have a feeling that most on this committee are aware of the cost of re-hospitalization, particularly when someone with moderate to late stage dementia is left alone or unsupervised. I also don't think that I have to convince any of you that this is a needed program. The funds run out nearly quickly as they are put in. Perhaps, though, we can consider this scenario:

There are teenagers whose parents have Alzheimer's disease, or one of the other irreversible dementias. Teenage girls whose father's may never walk them down the aisle. Teenage boys who won't be able to dance with their mothers at their wedding. There are older men and women, who waited their entire life to retire with the person they love, only to spend their latter years

stressing about finances, watching the person they've known best turn into someone completely unrecognizable to them.

When we cut respite, we are taking away from these people. They have nothing more to give. The disease has taken everything.