

Testimony of Elaine Cooley before the Appropriations Committee

March 4, 2011

Senator Toni Harp, Representative Toni Walker and members of the committee, my name is Elaine Cooley, and I am here today to testify in support of retaining the line-item funding for the Alzheimer's Respite program.

My brother and I were caregivers for our dear mother for approximately eight years. Caregiving is very lonely and stressful. You end up reversing your roles by being a protective parent to your mother 24-7. Knowing that there is help out there when you need it is very comforting. The respite program gives the caregiver a much-needed break from the awesome responsibility of caring for their loved ones.

I recall many times having lost my patience after hearing my mother repeating something over and over again. The guilt you feel afterwards. Loosing your patience will happen but having a respite can only lighten the burden and make these incidents of "loosing it" occur less. Respite care can assist in keeping your loved one in their home and delaying that difficult decision that your loved one needs placement. Statistics indicate that the Respite Care Program has successfully kept 85% of their clients in the home.

In caring for my mother I felt she was drifting away from us and we were unable to get her back. My brother would often describe the feeling of looking at her and seeing her physical being the same as always but a loss of her spirit, inner self and the twinkle in her blue eyes vanished. It is very sad to experience such a long period of endless losses. I often asked myself the question: Why does she have to leave me so slowly? There is a great sadness when you hear your mother say "it's not worth living anymore".

In time my mother was not able to respond socially to others. I can recall how much she enjoyed people and being around them. She would behave in a manner totally unlike her old self. Agitation and combativeness would be exhibited. I know now that this was the disease exhibiting her frustrations and lack of control in her life. You try and protect her from being embarrassed or frustrated as it breaks your heart when she behaves inappropriately. You do your best to make things “normal”. . **THE WAY SHE USED TO BE (repeat) THE WAY SHE USED TO BE.** An impossible task for sure.

You have to keep trying no matter how hard it may get. As small as buying a pair of sneakers, treating her to a McDonalds coffee or buying her favorite candy were big successes for me. A feeling that you are doing something to help her get through this heart wrenching life’s journey Looking to the Lord to guide you in what is best.

When leaving from my visits I would wave goodbye to her and sometimes she would wave back and for a quick moment I would have my Mom back.

A person who loved the birds and nature no longer understands their meaning. My daily visits are no longer interactive. You look into blank eyes that say nothing. You feel alone in this journey. Happy to know that she can recognize you when you enter her room for a visit.

She would often say, I love you very much” and that would give me the motivation that what I am doing is the right thing. How ironic, my mother’s only phrase towards the end was “I Love You”. Someone who loved me so deeply is left with one ability to communicate one phrase “I love you” I feel lucky to have such a gift from a wonderful mother. She had nothing left to give – she was fading away.

You often think about where this is all going.

As her caregiver I had become her advocate, guardian and protector. She looked to me for assurances that everything is OK that she was doing great. She was becoming very "childlike". I loved her so much no matter what she became through this illness.

When you truly love someone you endure anything in their life's journey and adapt to what comes your way. It is important that society can offer our caregivers support in helping them cope through their journeys. It is vital to retain the respite program.

Thank you for allowing me this opportunity to speak on behalf of the respite program for 2011.

Elaine Cooley

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