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# TESTIMONY

of  
Sandra Tatom  
Caregiver from Boise, Idaho

Before

THE UNITED STATES SENATE SPECIAL COMMITTEE ON AGING

Regarding

Needs of Family Caregivers

Washington, DC  
May 17, 2001

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Mr. Chairman and members of the committee, my name is Sandra Tatom and this is my husband Dean. We are here from Boise, Idaho and we are caregivers for Dean's mom.

### **BACKGROUND**

My 87 year old mother-in-law has not been able to live alone for approximately ten years. She has lived with us six months or more every year and with other family members, in her home town, the remainder of the year. We would have her for about three months and fly her home for a couple of months when she got tired of us. She is a woman of quiet dignity and fierce pride and she was "doing her part" by making beds and folding clothes. She always went everywhere we went and insisted on walking as far as she could before riding in the wheelchair.

This situation has changed recently. Mom had been in the hospital, in her home town, for two weeks when my husband, Dean, went to see her in February, 2001. She had not been out of bed in those two weeks. Dean got her out of bed, out of the hospital and soon had her in Boise. We believe this visit will be permanent. The family members, in her home town, are not able to keep her anymore.

### **NEEDS**

When mom got to our home in February, she was not able to walk without help, was incontinent, and totally confused. Dean and I did not have a clue as to how to care for her. I went to the store to find diapers and was overwhelmed by the vast array of products available. We could have used a class in *Caregiving 101*. It was very difficult to do the bathing, feeding, and bathroom assistance while still leaving her some dignity.

Dean is a retired school teacher and I work full time so the caregiving during the day is his. He needs a break in his caregiving and affordable, quality respite care is hard to find. Here again *Caregiving 101* would have been beneficial. Mom has improved somewhat since she has been in our home, but she has her good and bad days. Often I have wished there was someone I could call to consult regarding certain stages she is going through. Our community has **Dial a Nurse** for medical questions, we could use a **Dial a Caregiver** for caregiver questions.

We realize there are activities we will forgo in order to care for mom, but we know we have years ahead to do those activities. One of the big decisions we had to make was; did we want to give up our side business? We hope to continue with our one year old business. It took time to build this business and it is not something we can just stop now and pick up later. We have contacts, a customer base which we are building, money tied up in inventory, and we can not just put the business on a shelf and pick it up later.

We have a motorhome and trailer and we travel to shows and Pow Wows on weekends, set up a booth and sell southwestern and Native American products. Our goal is to supplement our retirement and pay for our travels. Mom went with us last year. We always made sure the motorhome was next to our booth where we could watch and help her as needed. Mom has always been a "goer" and enjoyed last year's trips. There were times she would be confused and not know what town or state we were in, but as long as she was with us she said she was happy. Our dilemma now is will she be strong enough to travel with us this year? If unable to do so, we need affordable weekend care for her.

This care could be: having someone come to our home on weekends and stay with mom, or finding an affordable adult care facility where we could leave her for the weekends. Affordable is the

foremost concern. We have checked around and in-home care cost approximately \$150 per day. The adult care centers, which will take people for short term care, cost between \$75 and \$150 per day. Available beds in those facilities are limited. Our business is just getting started and can't afford to pay that much for her care, and we personally can not afford it either.

We have heard from other caregivers that occasional, affordable weekend care or respite would be very beneficial for the caregiver's sanity. Employees work 40 hours a week and have their weekends off. Caregivers work 168 hours a week with no weekends off.

### **SUPPORT GROUPS**

The benefits of support groups were unknown to us. We did not realize that others were experiencing the same problems, worries and upsets we were experiencing. The first support group meeting we attended was connected to a retirement home and the members of the group had already placed their loved ones in the home. Dean went to a new support group meeting last week which was attended by people who were still in the "home-caregiving-stage." The majority of these people have been caregivers longer than us and were able to offer excellent advise in many areas. If we had a **Dial a Support Group** or Support Group 101, we might not have had to reinvent the wheel on our own.

The problem with attending and receiving the benefit of the support group meeting is finding affordable care for the loved one while attending the meeting.

### **OTHER CAREGIVERS' NEEDS**

I have talked to friends and acquaintances who were or still are caring for their loved ones at home. A friend of ours from Council, Idaho, a rural logging and ranching community, 125 miles from Boise, had taken care of her husband, with Alzeimers, at home. My friend had her own business and had difficulty finding someone to stay with her husband during the day. She could find no one to stay at night so that she could sleep. She finally had to place her husband in a facility because she was worn out.

Another friend from Council had to drive her mother to Ontario, Oregon, (about 70 miles) every day so that she could receive dialysis. This friend worked full time which forced her to admit her mother into a facility closer to treatment.

Another care giver from Council, who takes care of her ailing husband, said she has to have someone come who could get him into the car and take him for a drive. She just wanted a few hours at home alone.

These are a few cases of people I know who live in rural areas which receive little or no respite care for the caregivers. I am sure there are many, many more such cases.

### **CONCLUSION**

Mom has taken care of us through the years with total unselfish love and we are glad that we are able to care for her now. She has adamantly hoped she would never have to go into a facility. The people are too old and she would have nothing in common with them, she has always said. This is the last thing we want to do for Mom and we hope and will try with all our power to keep her with us. I know there are many people who have been at this intense caregiving stage longer than we have and they need respite and help.

We are not looking for nor do we wish to have a "give me program," but the availability of affordable respite would help us and many like us keep our loved one at home. We believe Funding of the National Family Cargivers Support Program would be less expensive than paying for facility care.