

May 3, 2004

Testimony by Jason Lentz

Good morning. My name is Jason Lentz and my sister, Jenny Lentz, joins me today. We are also with my wife Judy and our step dad, Robert Nagle.

We would like to share with you a story.

Imagine at the age of forty-seven/forty-eight during the prime of your life, a successful career, a happy, loving family and a true zest for life . . . your world is toppled upside down.

After years of deeply committed and impassioned service to your job, suddenly you are asked to leave.

Your usually pleasant home life becomes turbulent. Disputes are frequent and peace is sadly becoming increasingly rare.

You lose interest in those once precious things that made you get up out of bed on a miserable, cold and dreary day.

This is the story of our mother, Pauline Nagle.

In 1997, we began to notice drastic changes in Mom's behavior and mood over only a few months' time. Typically a workaholic, she no longer wanted to work. She lost interest in many of her cherished hobbies, including cooking and ceramics. One day we actually found her destroying years of hard work spent at the kiln. Mom also became increasingly moody, even cursing which was completely out of character for her.

Our family became worried, but we thought that perhaps she was going through an extreme menopause. Despite our urging, Mom consistently denied that anything was wrong. Only until she was let go from work did she finally agree to consult a doctor.

After several visits and only through the use of a PET Scan, we discovered that our mom's behavior and mood changes were not at all menopause, but a rare form of dementia known as Pick's disease. Pick's disease closely resembles Alzheimer's, with personality changes and disorientation that typically precede memory loss.

To say that this merely impacted our family would be a gross understatement. It has changed everything - causing extreme amounts of stress and heartache. At the time of diagnosis Jenny was just entering college. I was living away from home. Therefore, primary caregiving responsibilities initially fell upon our Step Dad.

As Mom's condition worsened, her care needs increased, requiring more personal care and constant supervision. As if the emotional pain was not enough now the financial

burden began to mount. Since Mom's income had completely ceased, the household was reliant upon my Step Dad's income that did not afford the amount of care that my Mom now needed. That is when my wife and I decided to move home and help care for her.

My family and I carry the weight of all the caregiving responsibilities. We cannot qualify for any assistance through the local Area Agencies on Aging besides the PA Family Caregiver Support program because Mom is under the age of 60.

May 3, 2004

Testimony by Jenny Lentz

"Hi", as my Mom would say.

Eight years have now passed and I have since moved home to assist my family with caring for our Mom. Her condition continues to deteriorate, particularly more dramatically in recent months.

Everything is a fight. She doesn't want to take a shower. She will sourly say "no" and then break into laughter and begin to clap. Mom seems to laugh a lot now. However, it is not a result of true happiness, the happiness we all experience when something funny occurs or the happiness of an intimate family moment. It is more often merely a symptom of this heartbreaking disease. Her laughter used to bring all of us joy, but now, it is a reminder of where we once were and where we are going.

Eating has become difficult for her. We try and feed her foods that are easy to swallow, like soup, puddings, and etc. to keep her body nourished. She is unable to control her bowel movements. Her physical safety is of primary concern too. She cannot sense danger. She constantly tries to wander outside and if successful would not be able to find her way home or be sensitive to oncoming traffic.

When I began a few moments ago, I said "hi". This is one of the two most frequently used words spoken by my Mom. The other is "Jenny". What does this mean? Does she remember me? Does she fully understand who I am or what is happening to her? More importantly, does she realize that we love her and that we are there beside her along this journey – until the end?

Unfortunately, these questions cannot be answered. The only piece of mind that my family and I can possibly have is to ensure that Mom is receiving the best possible care.

As a participant in the AoA program, Mom is now receiving two days a week of adult day care. She is doing exceedingly well in the program. She is able to interact with others and reap the rewards of the specialized care they are able to offer her. She is again making crafts which she was so fond of prior to diagnosis. They also have her doing physically appropriate exercises. In fact, some days, after coming home from day care,

she will continue to do some of those exercises, stretching and moving her arms in circles.

This program has also been a saving grace for my family. It has given each of us, my Step Dad, my brother, his wife and myself a chance to return to ourselves. It has allowed us to try and retain some of our former daily habits and continue moving forward in our own lives.

We are a young family. My Mom is now 54 and my Step Dad is also only in his mid fifties. My brother is approaching thirty and I am only a quarter of a century old. We have been robbed of the opportunity to share in the delights of a normal aging process. Our Mom will not be able to talk about her life experiences and share stories with her grandchildren. She will not be able to enjoy the luxuries of retirement. We are at the whim of this merciless disease.

But we have hope. Hope that through our support and our care that she is provided with the highest quality of life possible. Hope that there is still meaning, purpose and genuine happiness in her daily life. Hope that with each passing day, our strength persists.

Much of this hope is dependent on our ability to continue providing Mom with appropriate, quality care. The Alzheimer's Association AoA Program has been our only source of outside help. It is a lifeline in many of the ways I stressed above. We have hope that this program can continue through your support.

Thank you.