

A MESSAGE TO THE COURAGEOUS!

Caring for a dying loved one.

By Gary Radin written 1999

I am a 29 year-old caregiver living in Southern New Jersey who recently lost my father to early onset dementia. My father, Neil, was 58 when he died January 30, 1998. He was diagnosed with probable Pick's Disease, a frontal lobe dementia, in June 1995 following a year and a half of subtly increasing signs of what we thought to be depression. My dad was an entrepreneur and business executive who worked in business with my mom (now 54) for 30 years.

We were fortunate to get a "probable" diagnosis from a neurologist within two months after first seeing a social worker. When we found out this was a very progressive terminal illness, life changed quickly! I have a sister and brother-in-law (both 31) who decided with my mom and me that my parents should move in with me so we could care for Dad. We took immediate action and started very proactive care of nutrition including vitamins and other supplements for memory and general health. We researched everywhere for information and educated ourselves through the Alzheimer's Assoc., National Institute of Health and Rare Disorders Center.

We interviewed doctors that specialized in these diseases and set up a comfortable team we felt would be proactive. Nonetheless, we discovered it took us to be the ones who initiated the best care plan overall. This plan was made by asking an abundance of questions and taking all the information we could get and making the most of it.

We found very little financial support for in-home or day care. This was because the conditions of dementias are not recognized by health plans as medically necessary, and my dad was too young to qualify for state and other private funds. We found a county respite program and got care by qualifying for in-home therapies like speech and occupational. We had exhausted every resource. Additional care we paid ourselves, and it was costly at times.

Over the two and a half years that my mom and I cared for my dad in our new home, we made many provisions like install grab bars around the house and rented a stair lift to the second floor. Outthinking the next step of the illness was the challenge. Sometimes we guessed right and were ready for the next challenge, other times we only reacted. We used bath chairs and benches, a commode, automatic recliner, walkers and a wheelchair, and eventually a hospital bed with air mattress.

We had physical, occupational and speech therapists in the house many times each week. They taught us and we taught them how to find better ways to communicate, eat, exercise and move around the house. Our house became more than a home, it was a complete health care facility. Aids like food thickeners, nutritional drinks, lemon ice to induce swallowing, and a special prune and fiber mixture helped to regulate diet. All these things learned from the people and resources around us.

My father lost his speech quite quickly and we bought an augmentative speech device to assist him. It synthesized his typed words into audible sentences. This bought us six months more of communication. He also lost his mobility over time. He experienced injuries from falls, and we had

bad backs from constant lifting. He also attended a medical day care facility two or three days a week to be with other people and give us some rest.

As my father progressed into what could be called the third or final stage of his illness (about a year before he died), we could see major changes in his awareness and interaction, however he was still an integral part of the family. He couldn't speak, but we spent hours talking and sharing our lives with him. He could not walk, but we wheeled him to concerts and the movies. We did everything we could to provide the best quality of life even though the illness was taking it away.

We created a way for my father to participate in every way possible until he woke up one morning with severe aspiration. It had been progressively getting worse but we were managing it. After two and a half years of battling the disease, Dad was not able to eat without aspiration. He was treated and comforted in the hospital for a week, but even had difficulty with his own fluids.

We brought him home and set up Hospice to fulfill on my mothers promise to keep him home with us where he was comfortable to die. Hospice was amazing. They provided everything we could possibly need for his care and comfort. We brought in day care help and nurses at night to assist us with the short remaining time he had. My father stayed with us for 10 days until he died with us by his side.

I am sure that he always knew who we were until his last days of life. His hands would squeeze ours, as he would look in our eyes. He even gently rubbed my back the way he would when I was a child. There was definitely someone inside communicating with us in the small way that he could. In a way that still said love.

Our commitment to caring for him was unconditional. It was in return for the love and happiness he brought into our lives. There was no question about how to treat the man who gave my sister and I life and my mother the most devoted companionship for 35 years. It was not easy watching a life disappear and saying good-bye, but we knew we had done everything there was to do in the face of these circumstances. We were courageous!

I share this with caregivers, not to create sorrow or feelings sadness, but to demonstrate that our love, courage and commitment to the people we love gets us through the day. Somehow, some way, although it often seems impossible, we are stronger than we could ever imagine ourselves to be. It is through looking back that I realize the abilities we have as human beings to generate the abundance of energy, skill, resources and compassion to do such a monumental thing as provide this kind of care for another.

I honor you for your commitment to your loved one and for your courage to live life!