



*Secrets to successful
long-term care planning,
caregiving, and
crisis management*

Answers Aging

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The Unimaginable: A Reality for Two Families



The following **true** stories are illustrations of families who are currently faced with decisions regarding long-term care. They are included here to help you understand what happens to families when they are faced with some overwhelming decisions. Neither of these families did anything in the way of planning ahead financially for long-term care. Both ended up spending most of their assets to pay for the extraordinary costs associated with nursing homes and home care. The **secret** to avoiding financial devastation is to do whatever you can to prepare for the future.



An Early Diagnosis...

Steven and Patricia had been married for 30 years. Steven was 56 years old when he was diagnosed with Alzheimer's disease. The symptoms had been slowly creeping up on him. He had started to forget his way to his clients' homes. These were people he had done business with for 10–15 years. He was a very successful salesman.

One afternoon as he was attempting some household repairs, he hit his head on the bottom of a cabinet in the

kitchen and fell to the floor. He was not hurt badly, but after a day or two his neck really began to bother him. His doctor prescribed a cat scan of the neck and head. There was nothing wrong with his neck, just some muscle strain. But something more ominous was showing up on that CAT scan. Plaques and tangles in his brain. These are signs of Alzheimer's disease. Steven and his family were devastated. As Patricia looked back, she could see some of the signs...the forgetfulness, confusion, and difficulty concentrating on tasks. He was not able to read the newspaper without getting frustrated, and even after seeing the eye-doctor, he still couldn't seem to read the paper well. He struggled with directions, and with paperwork that he had been using for years in his business. He became short-tempered and easily frustrated. Patricia thought depression might have been the issue, but she never imagined this.

Steven remained at home with Patricia for several years. She cared for him constantly as the symptoms progressed. He would put on 5 shirts instead of one. Piles of socks littered the bedroom floor...he seemed to be searching for something. Steven appeared to know at times that he was having problems remembering and rationalizing. Other times, he simply did not know what he was doing, or why.

Patricia called me 2 years after Steven's initial diagnosis. She needed a break. She needed to get out of the house and start enjoying life again. She had been a prisoner in her own home for at least a year. She was afraid to leave her husband, even to go to the grocery. Their children were grown and had families of their own. They came by to help but it wasn't enough. Patricia was only 55 years old when I met her. She was a good, loving wife, but angry and disappointed that the best years they could have spent together were taken away.

Patricia hired some in-home caregivers to come to the house 3 days a week for a few hours at a time. She found the break she needed. Steven's health insurance would not pay for this type of care because it was not SKILLED care. It was considered long-term care. He would not recover, he would not get any better, and he would need this type of care for the rest of his life. Steven did not have to be admitted to the hospital for that diagnosis. His body was healthy. Potentially, he could live for 10 or more years.

Patricia and Steven are still privately paying for that care (they had no long-term care insurance). His initial diagnosis was 6 years ago. Steven is now living in a residential facility near their home. Patricia had to return to work to make ends meet. She is now 59 years old. Steven's retirement and all their investments are depleted.

Patricia asked me not too long ago: "Who will pay for MY care, when I need it? There is no private funding left. Who will care for me? Where will I be cared for?"

This story is true, and possibly one of the worst-case scenarios. However, it illustrates that planning ahead for long-term care is not just for people in their 70's and 80's. Long-term care can affect anyone at anytime. Life-style accidents, and diseases like Parkinson's, Multiple Sclerosis (MS), Alzheimer's disease, or strokes, can happen any time.

It Happened So Fast...

An ambulance pulls up to the Emergency Room door around 4a.m., with a 67-year-old male, complaining of right-sided weakness. He was getting up to use the bathroom, and suddenly realized that he was unable to walk,

or use his right arm. He managed to wake his wife and tell her that something was wrong. After a few minutes of analyzing the situation, his wife dialed 911.

Robert is rolled into the busy Emergency Room, and assisted onto a gurney in room #4. Nurses and doctors assess the situation, start IV's, and give him some life saving medicine that will stop the progression of the STROKE. His wife, Nancy, is in the waiting room and has now contacted all three of their children. Susan lives the closest, and is on her way. The boys, Tom and Joe, live out of town, and will make flight arrangements in the morning.

After several hours in the ER, a physician working on Robert's case approaches Nancy and Susan. He tells them both that there is good news, and there is bad news. The good news is: Robert is going to make it. He is stable and ready to be transferred upstairs to a regular bed. The bad news: Robert will need therapy and rehabilitative services to hopefully restore the use of his right arm and leg. He will need to learn to walk again, to dress himself, bathe himself, and transfer himself from the bed to a chair.

There is no guarantee as to how long the rehabilitation will take, and no guarantee of full recovery. But with hard work, there is hope.

THE RECOVERY PROCESS

Robert spends three nights in the hospital. Physical therapy and occupational therapy had been implemented immediately. At the beginning of day four, Robert is transferred to the local nursing home for skilled care and rehabilitation under Medicare. As long as Robert makes progress with his therapy, Medicare will pay for his care and room and board at the nursing home for up to 100 days.

Nancy is by his side every day, encouraging Robert to improve, celebrating every step that he is now making

with the assistance of a walker. Susan visits regularly. The boys have already come and gone, but call daily for updates and to send their love.

WORDS NO ONE WANTS TO HEAR

Three weeks into Robert's rehabilitation, a care-planning meeting is held, and Nancy is invited to attend. In a cramped conference room, doctors, nurses, and therapists sit around a large table. Nancy is informed that Robert has hit a plateau. This means that although he has made good progress over the last few weeks, he has now hit a point where he is making little to no further progress. He can walk with a walker, but will need assistance with bathing and dressing, and some assistance transferring from the bed to a chair.

THAT'S IT?

By Medicare rules and regulations, Robert no longer qualifies for skilled care. Nancy is provided with various options. Robert can go home, and potentially receive some home health care as long as he is deemed "home-bound". That home health care will consist of a 45-minute visit by a physical therapist and occupational therapist on alternating days. This type of home care is brief, and will probably not last much longer than a couple of weeks. It does not include and assistance with Robert's daily living needs, like bathing, dressing, and eating.

At the end of the week Robert is discharged from the nursing home and returns home with his wife, and his daughter Susan, to take care of him.

Susan is 35 years old. She has 3 children of her own and works full time. Her children are busy preteens and teenagers, who are involved in soccer, cheerleading, and basketball. Susan's husband also works full time.

Susan knows that her mother, Nancy, will be able to primarily care for her father, but will need some help. How much help is the question...

HOME FRONT

Robert is happy to be in his own bed, in his own home, with his wife. He has made enough progress to get himself up from the bed and into a wheelchair with minimal assistance. He can walk through the house with the aid of a walker. He cannot fully dress himself, or bathe without assistance.

Nancy spends her mornings helping Robert prepare for the day. She carefully helps him shower, dress, shave, and helps him to the bathroom.

Susan made it a point to visit daily for a couple of weeks after the homecoming. She now visits 2-3 times per week, allowing her mother to get out of the house and do a little shopping or run errands.

Nancy has decided to hire a nurse's aid to come to the house 3 days a week so that she can get some much needed rest and assistance with running the household.

Medicare does not pay for these services, so Robert and Nancy will be paying \$16.50 per hour, for 5 hours of care per day, 3 days per week, which equals about \$990.00 per month, or close to \$12,000/ year for in-home care.

This extra \$990.00 per month is not something they had factored in to their expenses upon retirement. **How many of us can easily afford to factor in the equivalent of a house payment on a monthly basis, so unexpectedly?**

CHANGES

Robert was stable for quite some time. A few months after returning home, he began feeling weak and not so well. Robert was diagnosed with pneumonia. As he became

progressively weaker, Nancy found it impossible to get him out of bed without assistance.

Robert was once again admitted to the hospital for a round of IV antibiotics, and then discharged after two days to his home, and to the care of his family.

Robert and Nancy increased the in-home care to 5 hours per day, 5 days per week, with assistance from Susan on the weekends.

Their out of pocket expenses were now reaching a level close to \$20,000 per year for in-home care.

Robert would live at home for another two years, with the assistance of his wife, daughter, and in-home care.

MORE CHANGES, MORE COST

As time progressed, Robert became increasingly confused and forgetful. Nancy cared for him as long as she could, but there came a time when Robert was requiring 24 hour a day care and assistance. She was no longer able to keep him at home.

After careful consideration, and with the help of her children, Nancy placed Robert in a local nursing home. The cost per day for a semi-private room was \$140. That adds up to \$4200 per month, or \$50,400 per year.

Nancy also had to add in the extra expenses of supplies and medications. These costs totaled about \$840 per month, or \$10,080 per year (about 20% over the cost of room and board).

The total bill for Robert's care had now jumped from around \$20,000 per year to \$60,480 per year!

Within two years Robert and Nancy's entire life savings and retirement nest egg was gone.

NEXT STEPS

Although not all nursing homes have Medicaid beds, this one had a few available. Robert was immediately put on the waiting list. Robert was on the waiting list for two years. When Robert and Nancy's money ran out two years later, he was allowed to stay in the same bed, but was now Medicaid eligible.

At that point, the federal and state government paid for Robert's care.

Nancy was left with only the home and a car, as well as her Social Security Income. The rainy day money they had set aside was now completely gone, along with any inheritance they had hoped to pass on to their children.

CONCLUSION

Robert and Nancy's situation was financially devastating. Obviously they had not planned ahead. Long-term care insurance would have paid for the home health aid and most of the nursing home costs associated with Robert's care. Robert would have been able to stay at home a little longer with the appropriate resources and financial assistance. Nancy would have been left with enough money to live comfortably and with peace of mind. Although long-term care insurance cannot take away the emotional pain of a family dealing with a chronically ill parent or spouse, it can alleviate the financial burden and provide security by preserving the family's assets.