

An

EXHAUSTING *privilege*

Writer **Pauline Hylton** cared for her aging father for six years before his death. She understands the challenges others face as they take on the role of caregiver and provides tips for coping.

WATCHED AS MY FATHER'S CHEST

moved slowly up and down. The room was dark and quiet. Nurse Faye had called the night before to tell me to come.

I woke mom from her room in the adjoining assisted-living facility. We trudged down the empty hallway to the nursing home. Mom slept in an extra bed while I rested in the cushioned chair, thinking back on my six-year caregiving journey, remembering what dad was like before his illness.

"Forty-two years of marital bliss," he'd declare. Pausing for effect, he'd finish with, "Forty-two out of 43 ain't bad." Then burst into boisterous laughter.

Caregiving had a similar feel: a few good years, a few bad years. More good than bad.

As I watched my father passing from this world to the next, I thought back to the day I'd asked my parents to move in with our family of four. Dad looked down over his glasses at me like I'd just gotten home after missing curfew. "It's going to be hard," he said.

"Yes, but what's hard is good," I replied naively.

I didn't know then that dad would

lose both legs to diabetes. Or that caring for him would place a tremendous amount of stress on my marriage. Or that my two teenage children would drift away as caregiving consumed more and more of my time.

I understand caregiving now.

According to Lynn Feinberg, a caregiving expert for AARP, there are approximately 61 million unpaid caregivers in the United States. That's a whole lot of caring. You might be one of those caregivers, or perhaps you will be some day. Here are some tips for navigating through the difficult but potentially rewarding caregiving journey.

Gather information and ask questions

When my friend's aging parents started to forget things, she went online and read all she could about Alzheimer's disease and dementia. That helped her gain enough knowledge to ask for help. Later, she discovered a support group where others faced the same problems.

"When I told them that my parents thought my husband was stealing money from them, they weren't surprised," my friend says. "Many of the members had experienced the very same thing."

The Internet provides a wealth of knowledge. But don't forget the team of medical professionals who assist you in caregiving. They're there to answer questions, so when in doubt, ask.

Schedule quality time

What's urgent often takes priority over what's important. So schedule time for the other important people in your life. There will always be needs while caregiving, but with some planning, you can keep balance in your life.

Have a discussion with your loved ones about what is important to them. Be sure to listen without preconceived ideas. Then schedule time to share with them. Put it on your calendar. You need to make time for other family members, too. Schedule it, and put it on the same calendar. Make it a priority.

Lose the guilt

Chances are, your loved one will want you to be with them most of the time. They feel safe and comfortable with you. But you can't do everything for everyone.

When the helper I'd hired got burned out and quit, I turned to my college-age daughter to stay with my father while I ran an errand. She called me while I was

out. “You’ve got to come home,” she said. “Grandpa is yelling, demanding 40 pieces of fried chicken for dinner. I don’t know what to do!”

I rushed home. My father pointed his finger at me and demanded the same menu.

I lost it. Hospice calls it caregiver breakdown. I knew then: One of us had to go, and Dad didn’t cook. I moved him into the nursing home a few days later. It was the hardest day of my life, but I couldn’t afford to feel guilty. I still had a husband and two children at home. They needed me, too.

Robert Kane, author of *The Good Caregiver*, recommends having a decision-making plan in place ahead of a crisis. To help you form that plan, Kane suggests hiring a case manager or checking into local agencies that provide information or services.

Better to make the plan ahead of time, rather than wait until your loved one orders a boatload of chicken.

Play to your strengths

Know what you bring to the task of caregiving. If you’re not an expert at everything, don’t try to be one.

“For instance, if your strength is organization, you should oversee the medical care and paperwork. That’s what I did when I cared for my mom,” Feinberg says. “My sister was a nurse. She handled all the physical care—that wasn’t a strength of mine.”

Take a break, get away

I was fortunate that one of my sisters was able to stay with our parents while my husband and I got away. In the hospice world, it’s called respite. You’re going to need it. Don’t be afraid to ask a relative to spend time with the people you’re caring for so you can have some time to yourself.

If you can’t do a few days away, get out for a movie or go shopping. A friend or neighbor may appreciate getting the opportunity to help you.

Lighten up

Caregiving can prove to be stressful and serious. So don’t forget to look for

humor in situations.

One day, I was upset that my dad blew raspberries in my direction. Tearfully, I mentioned it to my friend Miriam. “That’s hilarious!” she exclaimed as she roared with laughter.

At first, her reaction offended me. But Miriam was right. I’d just forgotten how to laugh. After that, I made a point of laughing more.

Rent funny movies. Watch your favorite comedy shows. As the adage says, “Laughter is the best medicine.” It is. Do it!

Prepare for end-of-life issues

Dad’s breathing became erratic, just like hospice had warned me it would. By the time I called my mom to his side, dad had died. I was at peace and so was my father. That’s because we prepared for it.

The day before my dad passed away, my friend and I visited him. I said all the things I needed to say. I sang and played my horn for him. Even though he seemed to be sleeping, my friend said his mouth moved to the words as he squeezed her hand. Mom said her goodbyes, too.

Talk about the death process with your loved one. Talk about it with your creator. Talk about it with others close to you. We all have to say goodbye at some point.

Be grateful for the privilege

The further I get from dad’s death, the more I realize what a privilege it was to care for him all those years. I learned about the love and commitment my parents had in their relationship. I was reminded that you take nothing with you when you die. And I learned that, one day, I’ll be in a similar position.

It reminds me of the verse from Psalms: “So teach us to number our days, that we may apply our hearts unto wisdom.” I want to live my life with that in mind.

Caregiving was hard. But it was good, too.

I think I’ll have fried chicken for dinner. ■

Know the forms of dementia

Alzheimer’s disease

The most common cause of dementia in people ages 65 and older

Symptoms usually appear after age 60, but early-onset forms of the disease can occur, usually as a result of a defective gene. Alzheimer’s disease usually progresses slowly, over seven to 10 years.

Vascular dementia

The second most common form of dementia

The disease is the result of damage to the brain caused by problems with the arteries that serve the brain or heart. Symptoms begin suddenly, often after a stroke, and might occur in people with high blood pressure or those who have had previous heart attacks or strokes. Often this form of dementia coexists with Alzheimer’s disease.

Lewy body dementia

Affects about 20 percent of people with dementia

Lewy bodies are abnormal clumps of protein that have been found in the brains of people with Lewy body dementia, Alzheimer’s disease, and Parkinson’s disease. The symptoms of this dementia are similar to Alzheimer’s disease, but patients fluctuate between confusion and clear thinking, visual hallucinations, and Parkinson’s disease symptoms such as tremors and rigidity.

Frontotemporal dementia

A less common cause of dementia that occurs between 40 and 70

This group of diseases is characterized by degeneration of nerve cells in the frontal and temporal lobes of the brain. Symptoms can include socially inappropriate behaviors, loss of mental flexibility, language problems, and difficulty thinking and concentrating.

SOURCE: MAYO CLINIC

When Alzheimer's comes home

One family's story of caregiving and coping

By **Jake Miller**

STERLING NEWBY IS ON A ROLL, ALZHEIMER'S DISEASE BE DARNED.

Newby, a 93-year-old man with a contagious smile and a full head of slicked-back gray hair, sat on the couch in the home of his daughter, Mary Hinson, rattling off story after story from his life.

At one point, he recalls in detail the story of how he met his wife, Marian, more than 69 years ago. As Marian, 89, and Hinson sit and listen, Sterling talks about the couple's first dance, when he realized how beautiful she was. Seconds later he pulls out a black-and-white photo of Marian from when they were first married.

To all outward appearances, Sterling Newby is an enthusiastic older person recalling the good old days. But his short-term memory has eroded, so those tales from long ago make up most of what he can remember.

"These are the stories I hear every day," says Hinson, a nurse who a year ago moved her parents into her home to make caring for them easier.

Alzheimer's disease is an incurable, fatal illness that attacks the mind, often proving more devastating for a patient's family than for the patient himself. Families must learn to cope with a loved one who ultimately will not remember who he is and will require constant supervision and help.

Newby, a witty former machinist and veteran of World War II, realizes he has memory issues. In fact, he, along with his family, saw the change coming about five or six years ago.

"I can remember before we were married better than two or three years ago," Newby says.



MARY HINSON moved her father and mother into her home to help care for her father, who has Alzheimer's disease.

On the rise

As the baby boomer generation continues to age, the number of people afflicted with Alzheimer's disease or other types of dementia is expected to increase.

1 IN 8

Americans 65 and older (5.2 million) has Alzheimer's disease

3.4 MILLION
are women

1.8 MILLION
are men

By 2030, 7.7 million people are expected to have Alzheimer's disease—a 50 percent increase from today's numbers

SOURCE: ALZHEIMER'S ASSOCIATION

doesn't make it easy.

During most days, Sterling and Marian have a simple routine. They do the laundry, wash dishes, and try to keep the house clean. They like to go for a short walk if the weather is nice.

Marian has gotten used to just listening over and over to Sterling's batch of old stories, and she insists she's prepared for when his memory worsens. "I just go along with it no matter what," she says. "If he goes to a [retirement] home, I'll go right with him."

Alzheimer's disease can baffle families. One day a patient might seem to have a relatively healthy mind. The next day, he might struggle to remember how to do simple tasks, such as letting the dog outside.

"It gets a little frustrating," Hinson says, "but you deal with it."

On most days, even when Sterling's memory is particularly bad, he can say something that keeps his daughter going. It's why Hinson will care for Sterling until she absolutely has to put him in a retirement home or hire in-home help.

"He tells me he loves me about 20 times a day," she says.

For him, the diagnosis wasn't particularly upsetting. Alzheimer's didn't hit him until his late 80s, and at 93 it still hasn't taken hold completely. "No, no, it doesn't bother me," he says.

Marian Newby has come to terms with what her husband faces. That

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