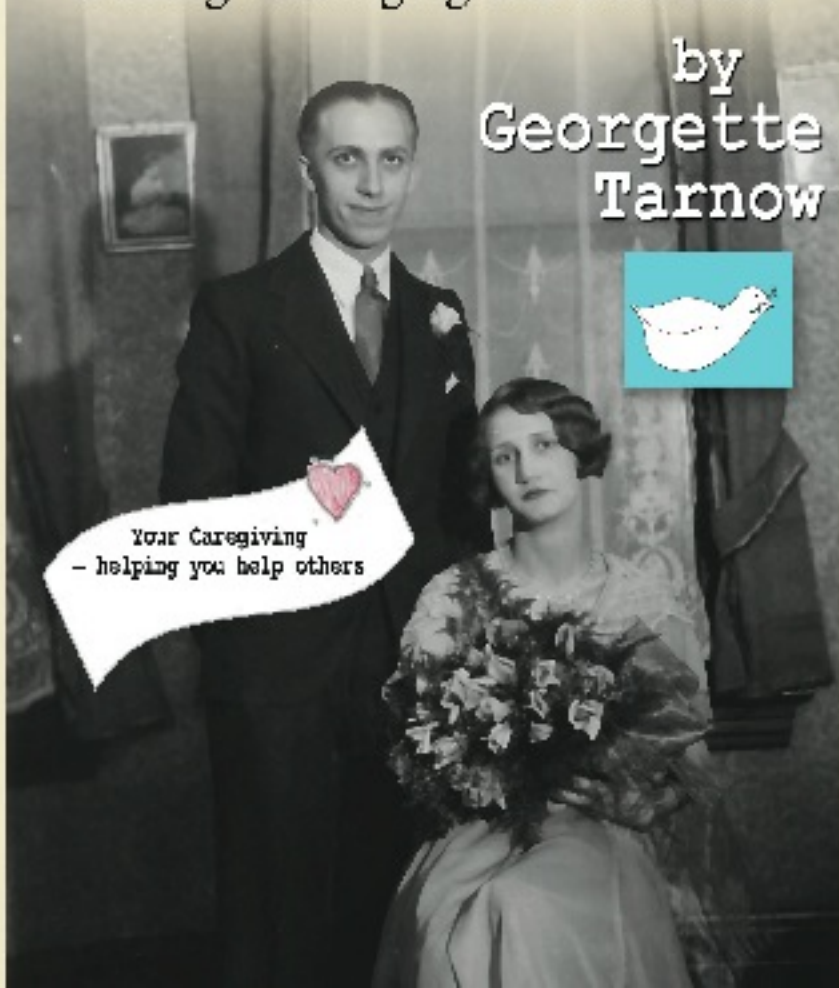


When Your Parent Becomes Your Child: Advice for Caregivers

...from a Daughter Who Spent 23 Years
Dealing with Aging and Dementia

by
Georgette H.
Tarnow



Your Caregiving
- helping you help others



This vivid account of the author's 23 years as a caregiver for her parents combines a common sense approach to caregiving with a deep understanding of the needs of the elderly and victims of dementia. With its rare glimpse into the frustrations and triumphs of long-term caregiving, this book will help you become a confident caregiver - even if you're not a healthcare professional.

When Your Parent Becomes Your Child

Advice for Caregivers

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The author's parents, George & Violette Tarnow, on their wedding day, April 4, 1931, taken by Violette's brother, WALTER SCHOEN.

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Dove and heart drawn by Mr. & Mrs. Tarnow's great-grandson, ETHAN C. LAPITAN. For more information, visit Ethan at www.Ethan.ws.

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INTRODUCTION

All sorrows can be borne if you put them into a story or tell a story about them.

-Isak Dinesen

THE FIRST TIME I ACTED as a caregiver was when my parents celebrated their wedding anniversary with a party at our house.

One of the guests was my Aunt Fanny (not her real name), my mother's sister. Fanny had had a mild stroke sometime previously but was functioning pretty well. However, when she went to our bathroom, she had a problem, so some of her urine wound up on the bathroom floor.

Mom asked me to clean up the bathroom. I did, but it wasn't easy and by the time I finished I was disheveled and sweaty. I can still remember the sweet, sick smell of her urine—I later learned she had diabetes. I wasn't happy to do the chore, but it had to be done. When I rejoined the party, Aunt Fanny loudly observed to me, "You look like hell!"

Well, yes, I suppose I did because it was a hot, dirty job cleaning up after her. That was my introduction to the world of caregiving. I was seven years old.

I'm not a doctor or nurse, although on several occasions when talking to doctors I was mistaken for a health care professional. My journey in caregiving led to learning a great deal about many diseases, drugs, and dementia. We were fortunate to have a family physician that made me his partner in caring for my parents.

I'm an attorney. My approach to law is as a sort of caregiver, as well. I specifically went to law school to help my extended family. I hated the notion that we could be threatened with lawsuits or become embroiled in any legal matter, and we would have to turn to a stranger for help.

We talked about caregiving in law school. I had a professor who cared for his senile father. He said we had a 50-50 chance of

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having to care for a parent with dementia. Little did I think then that I would be doing so within a year.

Why did I choose to be a caregiver? I don't think I ever consciously did. Being a caregiver is often not a role you choose--more likely it is something that happens to you; you are usually drafted and didn't enlist. Instead, I faced a long series of decisions and I "inadvertently" became a caregiver because of those choices.

When I was quite young one of my cynical friends said we should marry as soon as possible because any sibling who is unmarried when the parents need help becomes the caregiver until they die.

I was graduated from law school in 1980 and had every intention of working for the federal government, a good choice for women attorneys at that time. A government hiring freeze went into effect just as I was ready to enter the work force, though, so that was not an option. Job prospects in the private sector were rather dismal and became worse in 1981. Perhaps if I had been made the type of offer I couldn't refuse, such as a well-paid position with a law firm, my family's story would have been very different. As it was, I cared for my mother while I job hunted from home.

Maybe it was learned behavior. As a child, I was almost a daily visitor to the house where my mother grew up. Two of my aunts who never married shared this home with their mother, my grandmother, caring for her until the end.

Maybe it's what family does.

My dad swore Mother would never be put into a nursing home and I agreed with him. I personally believe if a healthy young person were to be put into a home, be over medicated, and be cut off from the outside world, that person would experience a mental decline. How much more so for the elderly person! My Aunt Min did go to a nursing home and had a positive experience. However, she was in a converted house with a very small group of patients. A devoted husband and wife team ran it.

I had two other aunts who needed care toward the ends of their lives. Their families took care of them, too. I wasn't a caregiver for them but I did visit them occasionally and help where I could. In addition to my own experience, I've spoken with many people who were or are caregivers for dementia and Alzheimer's patients.

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My story is a cautionary tale. I'm trying to talk to each of you so you learn from my mistakes and be encouraged by our successes.

I hope my experiences will help you, whether you are a full-time caregiver or someone who occasionally interacts with an elderly loved one.

CHAPTER ONE

BECOMING A CAREGIVER

I have nothing to offer but blood, toil, tears and sweat.

-Sir Winston Churchill

YOU BECOME THE PARENT—and your parent becomes the child: that happens when you realize your parent's mental or physical ability is slipping to the point where your roles have begun to change. When this role reversal occurs, it is not the happiest time of your life, but it need not be the worst.

The first hurdle is deciding when that day has come. It may come suddenly with obvious signs of mental deterioration, or the realization that something is wrong may take a long time. Some people rush the day. The first "senior moment" or mistake is to some a sign that the elderly person is incapable of caring for herself. Sometimes it is done maliciously; the adult child who wants the parent out of his life or to obtain control of any assets. Some forgetfulness occurs at any time in life—the misplaced homework of a child; the misplaced key of a young adult. Then suddenly the misplaced item is evidence of aging. Not necessarily so, without a pattern of problems.

A personality change—a person who was very authoritarian becoming meek or a person who was very sweet and loving becoming belligerent—also can signal the beginning of severe problems.

The other side of this is not recognizing the day has come. You may be in denial because you don't want it to be true and don't want to face the future without a parent to lean on, however subtle or seldom the leaning may be. If you're not seeing your parents regularly, are you truly aware of what's happening? I knew a very concerned daughter who lived out of state. She spoke with her elderly parents often by phone and thought they sounded fine. They reassured her they WERE

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fine. When she finally came to visit them, she was stunned to find her normally tidy parents living in absolute squalor.

I certainly did not want to accept that my parents were beginning to have health issues. My father announced to my mother and me one day that he thought his hearing was deteriorating and he wanted to look into buying a hearing aid. My mother and I promptly said no, your hearing is fine. It wasn't fine, and he was right about needing a hearing aid. But I remember vividly how I denied he had any problem because, as I realize now, I didn't want him to have a problem or to admit he was aging.

As I've mentioned, I was born when my parents were about 40, so these issues arose earlier in my life than they might for others. It doesn't matter. When you recognize that your parents are aging, you must deal with the inevitability of becoming an orphan: the fact that you are 20, 30, 40, 50, 60, or older is completely irrelevant to your emotions. I consoled myself with the thought that I could drop dead myself at any moment and not have to face being an orphan. Not a very healthy consolation.

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My mother had high blood pressure for many years. She started showing signs of senile dementia while I was in law school in the late 1970s. Mom became legally blind sometime after she became senile. This meant she could discern light and dark and some shapes. Dad had hearing loss, prostate cancer for which he had an operation, and heart disease. He had rheumatic fever when he was about 20 and apparently was left with an enlarged heart. He had two angioplasties unblocking the arteries around the heart. Both parents were found to be borderline diabetic. An EKG found heart damage to my mother's heart and she ultimately died of heart failure. Dad died of leukemia—14 hours, HOURS, after being diagnosed with acute myelogenous leukemia.

My sister and her husband and daughter lived just two blocks from my parents' house. My sister did what she could to help, but her husband was a semi-invalid and took up most of her time. No other family could help.

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Long Time Coming or Sudden

Sometimes, there is no mental deterioration as we normally think of it, but lapses in judgment. A friend of my parents was rather a tyrant in his own home. One day he was clearly ill, and his wife and grown daughters wanted to call for help. He ordered them not to call an ambulance; they obeyed—and to their horror—watched him die on the living room floor.

I went into the living room and found him sitting in a chair—and having chest pains.

My father was one of those without mental deterioration. However, one night I thought I heard him go into the living room. He often slept on the couch in there. I was about to roll over back to sleep, but I was nagged by the thought that he should be in bed. I went into the living room and found him sitting in a chair—and having chest pains. He knew he had a recently diagnosed heart problem and that he was probably having a heart attack. He didn't want to wake the household, though, so he just sat in a living room chair.

I got him into the car and to the hospital. He had had a very mild heart attack, caught in time, so the damage to his heart and his health was minimal. Afterwards I asked him to clarify his decision. He indicated he hadn't wanted to bother me.

"You didn't want to wake me and disturb my night's sleep?"

"That's right."

"So you thought you'd sit in the chair even though you knew you could die there?"

"Yes."

"So I would wake in the morning and find you dead, and you thought that was the best way to handle it?"

"Yes."

I slept very little, often only four hours out of 24, and very lightly, getting out of bed at any and every sound.

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This bit of thoughtfulness on my father's part was, of course, ridiculous. But its effect on my life was profound. From that day until my father's death some 10 years later, I never had a full night's sleep. I slept very little, often only four hours out of 24, and very lightly, getting out of bed at any and every sound. Parents of infants will understand the lack of quality sleep I experienced.

* * *

The family had known for several years that something was "off" with Mom, and we attributed it to her growing older, although she was not yet 70. I personally consider that an early age to experience noticeable mental deterioration. I have read, though, that the first Alzheimer patient, a woman treated by Dr. Alois Alzheimer, was 51 when treated and 56 when she died. Alzheimer's can strike the middle aged as well as the elderly.

The turning point for my mother was one day when she was making dinner. She made somewhat elaborate dinners and this one consisted of a meat course, vegetables, potatoes for mashing, and gravy. All were cooking at the same time, and she was trying to plan it so everything finished at the same time. This can be a bit tricky for anyone. I heard her in the kitchen clearly upset.

When I went to her, she said something along the lines of, "I can't, I can't."

She could not decide what to do next.

I calmed her down and led her to the porch. We had a glider that she loved to sit on in the evenings, and I had her sit there. I went back and found that the dinner was almost finished. Everything was cooked and ready to be put in serving dishes except the potatoes, which needed mashing. From that day forward, she was unable to cope with anything the least bit complex, even though this had been something she did virtually every day.

<p style="text-align: center;">She was unable to cope with anything the least bit complex, even though this had been something she did virtually every day.</p>

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She had been a good cook, so I tried to have her help me with small parts of the cooking chore. We often made waffles from scratch so I asked her to separate the eggs so the whites could be beaten. Separating takes a certain knack but it was something she had done effortlessly for many years. This time she just stared at the eggs and was unable to act. Heartbreaking.



This vivid account of the author's 23 years as a caregiver for her parents combines a common sense approach to caregiving with a deep understanding of the needs of the elderly and victims of dementia. With its rare glimpse into the frustrations and triumphs of long-term caregiving, this book will help you become a confident caregiver - even if you're not a healthcare professional.

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