

SECOND EDITION



AGING with a PLAN

How a Little Thought Today Can
Vastly Improve Your Tomorrow

Sharona Hoffman, J.D., LL.M., S.J.D.

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CAN VASTLY IMPROVE YOUR
TOMORROW

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This title is also available as an e-book.

In memory of my parents,
Rabbi Morton and Aviva Hoffman

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INTRODUCTION AND MY PERSONAL STORY

As often happened in those days, my lunchtime conversation with a colleague drifted to the subject of eldercare. My husband and I had been immersed in caring for elderly relatives who were in their mid-80s and beyond. During an 18-month period in 2013 and 2014, we lost my mother, who died at the age of 84; Andy's mother, who died at 93; and my father, who died at 87. My friend revealed that she was coordinating care for her mother, who was in her 90s, had advanced dementia, and lived in another state. I said that sometimes I felt that our parents were lucky because at least they had us to help them, and that I have begun to worry about my own aging because Andy and I have no children. Then my friend surprised me by saying that she enjoys a very close relationship with her only son, but what she fears most about aging is that he will come to dread visiting her and will consider contact with her to be an unwelcome obligation. Having a devoted child, therefore, was hardly a comfort when she contemplated her later years.

This book, *Aging with a Plan*, began with my own effort to identify strategies that I could adopt to minimize the potential pitfalls of aging. It also grew out of a desire to help my contemporaries who may find themselves suddenly immersed in caring for elderly relatives, a sometimes overwhelming task for which little in life prepared us. It is meant to be a concise but comprehensive resource for middle-aged people who have much to gain from thinking ahead.

This second edition is fully revised and updated. It was completed in 2021, a year that will long be remembered for the COVID-19 pandemic.

In the process of researching and writing, I have learned a great deal. Too many elderly individuals refuse needed professional caregiving because of its costs and the loss of autonomy it involves; some undergo aggressive medical interventions that exacerbate rather than improve their conditions; and others end up in facilities that are inadequately staffed and whose services at times border on neglect. Yet I have also found much reassurance. I am convinced that many other people in their 40s, 50s, and early 60s can benefit from the knowledge I gained and from investing some effort in planning for their later years as well as for those of their loved ones. As I learned the hard way, in the midst of crisis, it is very difficult to make the best possible decisions if you have never contemplated the matter at hand.

WHY I WROTE THE BOOK

“Shoot me before I get to be like my [mother, aunt, grandfather]” is an only half-joking comment I’ve often heard from individuals who are involved in caring for the elderly. Yet, as much as Americans plan for their futures earlier in life, few of us dare think about and plan for frailty, which could extend over years or even decades of our lives. *Aging with a Plan* aims to change that.

The book is anchored in both my personal experience and my professional expertise as a professor of law and bioethics at Case Western Reserve University. I am also a member of the Ethics Committee at Cleveland’s University Hospitals, which often grapples with difficult treatment decisions for incapacitated elderly persons who do not have other decision makers. My interest in issues of health law, bioethics, and caregiving stems in part from a 15-month period in the mid-1990s in which I suffered my own medical crisis and shortly

thereafter became a caregiver for my then 65-year-old mother, who underwent extensive treatment for breast cancer.

The first time I thought seriously about my mortality was in the spring of 1994. I awoke in the early morning hours of May 4 to the most severe abdominal pain I had ever experienced. I struggled to think clearly. Was it a stomach flu? Was it menstrual cramps? I got out of bed and walked doubled-over to the bathroom. I took two aspirin, fought my urge to shriek in agony, and tried to find the least uncomfortable position, alternately sitting, lying down, and pacing in my small one-bedroom apartment. I could not believe how piercing and unrelenting the pain was, and nothing would relieve it.

I was 29, single, and had no family in Houston, where I had been living for four years. It turned out that I had a large (eight by five by five inches), borderline malignant ovarian tumor. I underwent major surgery, but, to my relief, I did not need chemotherapy or radiation. As soon as the tumor was discovered, my parents, who lived in Michigan, rushed to Houston, and friends remained by my side so that I was rarely left alone until well after my hospitalization. Six weeks after the surgery, at the end of June, I resumed my full-time work schedule. I weighed 98 pounds, having lost 10 pounds, and tired easily, but life slowly returned to normal.

And then came a phone call in the third week of November 1994 that would dramatically change everything once again. My mother, or Eema, as we called her in Hebrew, was diagnosed with breast cancer following suspicious findings on a routine mammogram. She wanted to take advantage of my living in Houston and have her surgery at the renowned MD Anderson Cancer Center. Thus, my parents and three younger sisters made a pilgrimage to Texas, and my one-bedroom apartment turned into Hoffman family headquarters.

Eema had a full mastectomy to remove her right breast along with 12 lymph nodes on December 7, 1994. The surgery was successful, but we soon learned that 6 of the lymph nodes

were positive for cancer. She would need both chemotherapy and radiation, with treatment lasting well into the summer.

I don't remember any serious family discussion of next steps. Instead, I remember only Eema's announcement:

I'm going to stay in Houston for all of my treatment. I will live with Sharona, and everyone else can visit when you want to.

I had not contemplated this possibility before, but I did not object. It was reasonable for Eema to want to be treated at a premier oncology center, so I embarked on this journey with her, though not without trepidation.

And thus began what ironically became one of the most wonderful periods of my life. I had not been particularly close with Eema during my first three decades. She was more a strict disciplinarian than a friend. By contrast, the nine months I spent with Eema in Houston were a gift that introduced me to a person I had never known before. Eema suddenly blossomed into a gregarious, adventurous, and fun-loving woman who looked and acted decades younger than her 65 years.

We attended numerous lectures and community events. We also frequently went to the theater and took advantage of half-priced tickets that were available one hour before the show began. Eema even developed a surprising interest in eating out, though she had previously always preferred to eat modest meals at home.

I would tease Eema and tell her that she was exhausting me with all this running around.

"You're supposed to be sick, and I'm supposed to be having a very boring year, stuck in the apartment taking care of you. Instead, you don't let me stay home at all."

In response she would squeal in delight and acknowledge that she didn't recognize herself.

"Who knows what's really in this chemo? It is giving me a complete personality overhaul."

Eema's energy, initiative, and magnetism impressed me to no end. Her health care providers loved her. My friends adored her. Even Freddie, the woman who delivered our mail, was extremely fond of her because Eema made a point of going downstairs to the mailboxes to chat with her as she worked. Freddie asked about Eema whenever she saw me for years thereafter.

Eema completed her eight cycles of chemotherapy and then underwent six weeks of radiation treatment. She left Houston in August 1995 and was cancer-free for almost eighteen years. She died on May 17, 2013, of what turned out to be pancreatic cancer.

I often think back to the dramatic years of 1994–95. I was both a patient with a serious illness and a caregiver for a prolonged period of time. I learned firsthand about the triumphs of modern medicine and the challenges and complexities of the health care and insurance industries. I also learned a lot about caregiving. I know how important family, friends, and community are in difficult times. And I have an acute awareness of how much time, effort, and money may be required to meet all the needs of a loved one who is very ill.

Eema and I were sustained by the devotion of our friends and by our own close bond. We looked forward to visits, phone calls, and mail, and we made a point of going out and interacting with others as often as possible. The many months we spent together were also a highlight for me because I felt at my most useful, and Eema was generous in expressing her gratitude every day. For others whose health is failing, it is very challenging to maintain robust social lives and a sense of purpose. The importance of social interaction and feeling useful are major themes throughout this book.

My experiences led me to become increasingly interested in medical matters and ultimately to devote my career to health law and bioethics. A decade after graduating from Harvard Law School in 1988, I returned to school to pursue an advanced

degree (LL.M) in health law at the University of Houston Law Center and then obtained a faculty position at Case Western Reserve University (CWRU) School of Law, where I serve as codirector of the Law-Medicine Center. I have also earned a doctorate (SJD) in health law from CWRU.

I have written *Aging with a Plan* in order to find answers to the many questions and anxieties that I have about growing old without an obvious source of informal caregiving. In 2013, Eema suffered terribly during a 10-day hospitalization before her pancreatic cancer was diagnosed, and we switched her to hospice care for the final two days of her life. But in some ways, she was very fortunate. Once it was clear that Eema's condition was serious, her four daughters dropped everything and rushed to be with her, and we left the hospital only to get a few hours of sleep at night. We also were not shy about pressing doctors and nurses to do everything possible to relieve her pain, and we easily reached consensus about pursuing comfort care when it was clear the end was near. Eema took her last breath while deeply asleep and surrounded by her children.

Thereafter, our father, though he was devastated by the loss of his wife of 54 years, enjoyed the benefits of having four devoted daughters. One of my three sisters resided minutes away and was extremely involved in his care. She visited frequently, filled his pill boxes, and coordinated all of his care. The rest of us, who lived out of state, called multiple times a week and visited as often as we could. When it was clear my father was dying in late 2014, we once again gathered together and held a round-the-clock vigil by his bedside during his final days.

My old age will inevitably be different. My husband, Andy, is seven years older than I, and we have no children and no large, extended family. Moreover, in October 2013, at the age of 55, Andy was diagnosed with Parkinson's disease. Although this illness progresses slowly, he will become increasingly disabled and will likely need assistance from paid caregivers, which could deplete our savings. These circumstances worry me. If

I reach old age and experience the inevitable deterioration of my health, will I have a strong support network, as I did when I was sick at 29? In the absence of children, will there be trustworthy people who can regularly help me with medication, transportation, finances, and the like? If I live independently late in life, will I have the fortitude to give up driving when that is prudent or to know when it is time to seek professional caregiving or move to a nursing home? And what if I become one of the millions of elderly people with cognitive impairment and dementia? How can I even begin to contemplate that possibility?

Over the years, I have learned that many share my anxiety about having to be self-reliant late in life. What can be done? One option is to simply focus on enjoying the present and not “waste time” fretting about potential future misfortunes. But a need to manage and plan is deeply embedded in my nature. Letting the chips fall where they may is not. You can always hope to die in your sleep, but this is very unlikely. According to one study, only 10 percent of people who die of natural causes experience sudden death with no prior diagnosis of a potentially fatal illness.¹ Some torments, like the onset of dementia, are currently outside of human control. But other hardships, like social isolation and a lack of purpose can be overcome or be avoided with sufficient effort.

In the spring of 2007, I spent a sabbatical semester at the Centers for Disease Control and Prevention, working on public health emergency preparedness. All of us have recently experienced a public health emergency in the form of COVID-19. We have seen the tragic consequences of failing to plan for a global pandemic and of not taking it seriously enough. COVID-19 also vividly demonstrated how unpredictable life

1. Mary Elizabeth Lewis et al., “Estimated Incidence and Risk Factors of Sudden Unexpected Death,” *Open Heart* 3, no. 1 (2016): e000321.

can be. Whatever your age, you may be healthy one week and gravely ill the next, needing trusted people to make critical decisions for you. If we are not educated about the challenges of our later years, we may face unnecessary suffering and avoidable disasters. This book, therefore, serves as a guide to aging preparedness.

A FEW FACTS AND FIGURES

The challenges of aging are of utmost importance to American society and will only grow in significance in the coming years and decades. If you are like me and are past the half-century mark, you are among a large wave of people who are changing the age demographics in this country.

In 2019, 16.5 percent of the population, or 54 million people, were age 65 and over;² up from 3.1 million in 1900.³ Those who are 85 years old and older numbered 6.5 million in 2018, compared to just over 100,000 in 1900. Experts predict that by 2040, the 85 and older population will grow to 14.4 million.⁴

“Baby boomers,” defined as those born between 1946 and 1964, began turning 65 in 2011. The 65 and older population is projected to expand to 78 million by 2035 and to constitute

2. Erin Duff, “Share of Old Age Population (65 Years and Older) in the Total U.S. Population from 1950 to 2050,” September 28, 2020, <https://www.statista.com/statistics/457822/share-of-old-age-population-in-the-total-us-population/>.

3. Administration for Community Living & Administration on Aging, “2019 Profile of Older Americans,” Administration for Community Living & Administration on Aging, <https://acl.gov/sites/default/files/Aging%20and%20Disability%20in%20America/2019ProfileOlderAmericans508.pdf> (May 2020): 5.

4. Administration for Community Living & Administration on Aging, “2019 Profile of Older Americans,” 3.

21 percent of total US residents.⁵ In fact, the US Census Bureau predicts that in 2035 seniors will outnumber children under 18 in the United States, of whom there will be only 76.7 million.

In 2019, life expectancy in the United States was 76 years for males and 81 years for females.⁶ Life expectancy is an average that varies with age, and thus the outlook is even better for individuals who have already lived to be 65, because they have survived the hazards of infancy, childhood, and young adulthood.⁷ Women who are now 65 can expect to reach age 85 and their male counterparts can expect to live to be 83.⁸

Although many seniors achieve longevity, they do not necessarily do so in good health. According to the National Council on Aging, 80 percent of older adults have at least one chronic condition and nearly 70 percent of Medicare beneficiaries have two or more.⁹ Most commonly, seniors have hypertension (67 percent of men and 75 percent of women), heart disease (28 percent), diabetes (28 percent), cancer (19 percent), stroke (9 percent), and arthritis (54 percent).¹⁰

5. US Census Bureau, “The U.S. Joins Other Countries with Large Aging Populations,” US Census Bureau, updated October 8, 2019, <https://www.census.gov/library/stories/2018/03/graying-america.html>.

6. Erin Duffin, “Average Life Expectancy in North America for Those Born in 2019, by Gender and Region (in Years),” *Statista*, September 20, 2019, <https://www.statista.com/statistics/274513/life-expectancy-in-north-america/>.

7. Maggie Koerth-Baker, “Death of a Caveman: What Swedish Babies and the Stone Age Can Teach Us about Life Expectancy and Income Inequality,” *New York Times Magazine*, March 24, 2013, 14.

8. Administration for Community Living & Administration on Aging, “2019 Profile of Older Americans,” 5.

9. National Council on Aging, “Healthy Aging: Fact Sheet,” National Council on Aging, revised July 2018, <https://d2mkcg26uvglcz.cloudfront.net/wp-content/uploads/2018-Healthy-Aging-Fact-Sheet-7.10.18-1.pdf>.

10. Administration for Community Living & Administration on Aging, “2019 Profile of Older Americans,” 17.

Furthermore, as of 2021, 6.2 million Americans were afflicted with Alzheimer’s disease, almost all of whom are seniors.¹¹ Many more live with other forms of dementia.¹² Recent research, however, provides some encouraging news concerning dementia. One study found that dementia rates among US residents who are 65 and older dropped from 12 percent in 2000 to 10.5 percent in 2012.¹³ Several other studies confirm a decline in the prevalence of dementia in the developing world.¹⁴ This drop is likely attributable to better education and health, including control of blood pressure and cholesterol through medication and good health habits such as regular exercise and proper nutrition.¹⁵

11. Alzheimer’s Association, “2021 Alzheimer’s Disease Facts and Figures,” *Alzheimer’s & Dementia* 17, no. 3 (2021): 1–104, at 19. More specifically, according to the Alzheimer’s Association, “the percentage of people with Alzheimer’s dementia increases dramatically with age: 5.3 percent of people age 65–74, 13.8 percent of people age 75–84 and 34.6 percent of people age 85 or older have Alzheimer’s dementia.”

12. Alzheimer’s Association, “2021 Alzheimer’s Disease Facts and Figures,” at 19.

13. Péter Hudomiet, Michael D. Hurd, and Susann Rohwedder, “Dementia Prevalence in the United States in 2000 and 2012: Estimates Based on a Nationally Representative Study,” *Journals of Gerontology: Series B* 73, suppl. 1 (2018): S10–S19.

14. Olivia Petter, “Dementia Rates Are Falling in Europe and the US and Experts Credit Decline of Smoking,” *Independent*, March 21, 2019, <https://www.independent.co.uk/life-style/dementia-decline-rates-smoking-tobacco-prevention-study-harvard-school-public-health-a8833136.html>; Alzheimer’s Research UK, “International Research Shows Dementia Rates Falling by 15% per Decade over Last 30 Years,” Alzheimer’s Research UK, March 20, 2019, <https://www.alzheimersresearchuk.org/international-research-shows-dementia-rates-falling-by-15-per-decade-over-last-30-years/>.

15. Gina Kolata, “Dementia on the Retreat in the U.S. and Europe,” *New York Times*, August 3, 2020, <https://www.nytimes.com/2020/08/03/health/alzheimers-dementia-rates.html>.

Nevertheless, experts estimate that dementia cost American society a staggering \$305 billion in 2020.¹⁶ Much of the burden of caring for this population falls on family and friends. According to the Alzheimer's Association, over 11 million Americans provide unpaid care for Alzheimer's disease and other dementia patients, supplying approximately 15.3 billion hours of care in 2020.¹⁷

But many individuals lack adequate support systems. Federal government statistics reveal that in 2019, women who were 65 or older were twice as likely to live alone as men in that age group (9.7 million vs. 5 million). Overall, 28 percent of seniors who are not in facilities live by themselves.¹⁸ The Alzheimer's Association estimates that this figure includes 26 percent of dementia patients who do not live in long-term care facilities.¹⁹

The childless

A significant segment of the US population remains childless throughout life. As of 2018, according to the Pew Research Center, 14 percent of women in the age group of 40–44 had never given birth.²⁰ In 1976, the figure was only 10 percent.

16. Alzheimer's Association, "Costs of Alzheimer's to Medicare and Medicaid," Alzheimer's Association, March 2020, http://act.alz.org/site/DocServer/2012_Costs_Fact_Sheet_version_2.pdf?docID=7161.

17. Alzheimer's Association, "2021 Alzheimer's Disease Facts and Figures," 36.

18. Administration for Community Living & Administration on Aging, "2019 Profile of Older Americans," 4.

19. Alzheimer's Association, "2020 Alzheimer's Facts and Figures," 425.

20. Gretchen Livingston, "They're Waiting Longer, but U.S. Women Today More Likely to Have Children than a Decade Ago," Pew Research Center, January 18, 2018, <https://www.pewsocialtrends.org/2018/01/18/theyre-waiting-longer-but-u-s-women-today-more-likely-to-have-children-than-a-decade-ago/>.

In her moving memoir, *Blue Nights*, Joan Didion writes about the death of her only daughter less than two years after she lost her husband. In a poignant passage with particular resonance for me, she recounts her efforts to fill out medical forms in physicians' offices:

Sitting in frigid waiting rooms trying to think of the name and telephone number of the person I want notified in case of emergency.

Whole days now spent on this question. This question with no possible answer: *who do I want notified in case of emergency?*

She could think of no one and left the space blank on the paper.²¹ Many others who lack close relatives must face similar dispiriting moments. A major purpose of this book is to offer resources and recommendations for those who will be aging without nearby family members to whom they can turn for assistance.

WHAT THE BOOK COVERS

Aging with a Plan offers one-stop shopping to those who wish to prepare for their own aging and that of loved ones. I explore a variety of relevant social, legal, financial, and medical issues. I elaborate on the importance of developing a robust social life, intellectual interests, and ways to maintain a sense of purposefulness that will not fade late in life. In the words of a friend who is a geriatric social worker, the key to good aging is to “stay active physically, mentally, and socially.”

In general, my guiding question is this: What should middle-aged individuals contemplate, study, decide, and do to be as well-equipped as possible for their own aging and that of loved

21. Joan Didion, *Blue Nights* (New York: Vintage, 2011), 185.

ones? Furthermore, at a broader, societal level, what cultural, attitudinal, and legal changes are required to improve the prospects of the elderly, especially those who cannot count on others to care for them? What should baby boomers, with their strong political voice and economic power, be striving and lobbying for?

In brief, I address the following topics in this book's chapters.

- In Chapter 1, I explore some of the costs that individuals may incur after retirement and discuss the importance of retirement savings and of obtaining professional financial advice. I provide guidance as to how to obtain financial counseling and begin a savings program and analyze in detail two particular financial products: long-term care insurance and reverse mortgages.
- Chapter 2 describes several types of retirement communities with a special focus on continuing care retirement communities. I argue that seniors should not lightly dismiss the idea of living in a community setting because of the importance of maintaining social interaction and intellectual and civic engagement throughout life.
- A major concern for independent seniors without close family members is whether anyone will be available to help coordinate their care, pay bills, and provide the support that others receive from their children and nearby relatives. In Chapter 3, I explore a variety of emerging options for professional help, namely geriatric care managers, daily money managers, elder law attorneys, professional organizers, and experts who can assist with adapting a home to accommodate disabilities or with preparing it for sale.
- In Chapter 4, I discuss and critique a variety of documents that are essential for purposes of legal preparedness: durable powers of attorney for health care, living wills, organ donation forms, advance directives for