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Navigating Your Later Years

for
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Consider healthcare
and insurance options

Talk with family about finances
and other tough issues

Learn about housing choices
and downsizing

Carol Levine

Director, Families and Health Care
Project, United Hospital Fund

Navigating Your Later Years

AARP

**for
dummies[®]**
A Wiley Brand



Navigating Your Later Years

by Carol Levine

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dummies[®]
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Navigating Your Later Years For Dummies®

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Introduction

If you've opened this book, then you're thinking about how best to navigate this next stage of life, whether for yourself or for a relative. (For simplicity, I'll refer to "you.") Here, you find a road map to move forward, step by step.

Turn back, for a moment, to the cover of this book. What I want you to notice is the illustration: a person at the middle of a constellation of people, activities, and services. The icons suggest a full and satisfying life — family, of course, as well as social connections, healthcare and healthy living, community involvement, and resources. The goal of this book is to help you put everything in place now for the best possible future, both for the person at the center and those who care about, and may care for, that person.

Because you've picked up or downloaded this book, you probably already know that you have questions. What you may not know is the broad scope of decisions, services, and choices that may arise. In my many years in the fields of health policy, aging, and family caregiving, I have seen that people often start with a specific question about topics such as buying long-term care insurance or choosing an independent- or assisted-living facility and soon find that they need to explore many other avenues as they pursue their goals of good health, independence, choice, and quality of life.

Times have changed, and there are many more options than there were decades ago, so keep an open mind. Learning about these options can be challenging, but finding the answers you need and creating a comprehensive and workable plan that fits your needs are well worth the effort. Like any other major decision in life, planning requires weighing risks and benefits, being flexible, and staying open to change. It can be unsettling. Some of your assumptions and preconceptions may be challenged. Even though I have many years of experience in this field, writing this book has given me new insights into the difficulties that individuals and families face in planning. I have new respect for their diligence and devotion.

About This Book

I wrote this book to offer the broadest possible view as well as to provide information about specific topics. You'll find out about

- » Modifications you can make to your home so you can stay independent and live at home as you age
- » Downsizing your current home or planned move
- » Options for housing such as independent and assisted living or specially created communities
- » Multigenerational living
- » Personal care and homemaker services
- » Transportation and other community services
- » Medical care, which may be primary care, preventive care, hospitalization, or rehabilitation services
- » Financial issues and tips for managing money
- » Advance directives so your wishes concerning healthcare are known
- » Wills and estates

Throughout this book, I present you with a range of options to consider, always with the caveat that no one solution works for everyone. You may, for instance, need to make modest adjustments to your home, or you may need to move to an assisted-living community. I also include your family, partner, neighbors, and friends — and the community in which you live — as crucial factors in decision making. Remember too that the emotional aspects of a plan are often underestimated but can determine its success or failure.

I've read and contributed to many books that tackle one subject at a time. They are valuable resources but don't cover the wide landscape. This book is a blend of what I've learned from all these approaches, but it presents the big picture and then zeroes in on the practical, hands-on information that is often difficult to find in one place.

You, the reader, decide how to use this book. It is organized so that you can easily find the topics you want to know more about and skip the ones that don't apply to your situation. There are many ways to get to various chapters and parts of chapters. You don't need to read the chapters in order, although I would recommend at least skimming the chapters in Part 1 for an orientation to the book's broad perspective. Of course, you can always come back to these chapters after you have reviewed the areas you want to concentrate on.

Many chapters have separate sections called *sidebars*, which are brief digressions into history, public policy, little-known facts, or other kinds of information that are not essential to the text but add to its depth. You can safely ignore them, but I hope you at least dip into a few.

Every chapter has web links to other resources to help you get more specific information about a particular topic, find information about your state's regulations, or delve deeper. You may note that some web addresses break across two lines of text. If you're reading this book in print and want to visit one of these web pages, simply key in the web address exactly as it's noted in the text, pretending that the line break doesn't exist. If you're reading this as an e-book, just click the web address to be taken directly to the web page.

This book is meant to serve as a reference, so you don't have to commit any information to memory. It's all there, waiting to be read and re-read.

Additionally, two other *For Dummies* books from AARP — *Social Security For Dummies* (by Jonathan Peterson, published by Wiley) and *Medicare For Dummies* (by Patricia Barry, published by Wiley) — are helpful adjuncts to this book and offer more detail about those two important public programs.

Foolish Assumptions

This book makes a few assumptions about you, the reader:

- » You probably don't know a whole lot about various aspects of housing, finances, legal directives, and medical coverage you'll want or need to consider as you age. And even if you have some professional or personal background in the field, you can benefit from new information and different perspectives.
- » You may be starting to plan, or already planning, for yourself or your spouse or partner. You probably have some time to plan before the need arises — but don't underestimate how long it may take.
- » You may be starting to plan, or already planning, for an older person such as a parent. The time for planning in this situation may be short; it may follow a health crisis. You need help now. But don't make quick decisions that will be hard to reverse.
- » You may be comfortable using the Internet to find additional resources.
- » You are worried about making the best choices and how to pay for them. Rest easy: You are not alone.

Icons Used in This Book

Throughout the book, you will see several icons that draw your attention to certain kinds of information.



TIP

The Tip icon links to an additional resource or offers advice about the topic discussed in the preceding text.



REMEMBER

The Remember icon is not a literal order to memorize the information but a word to the wise, a reminder of what you should be considering.



WARNING

The Warning icon signals important information that alerts you to a potential problem — for example, a fraudulent practice or a scam aimed at older adults.



TECHNICAL
STUFF

Technical stuff is just what it sounds like — more detailed information than you don't absolutely need but that you may find helpful just the same.

Beyond the Book

As they say, “But wait! There’s more!” Online you’ll find extras that come with the book. *For Dummies* Cheat Sheets are handy online reference tools that you can use over and over — for example, a list of questions to ask when you visit an assisted-living facility or some easy fixes you can make to your home to prevent falls. To get the Cheat Sheet for this book, simply go to www.dummies.com and search for “Navigating Your Later Years For Dummies Cheat Sheet” in the Search box.

Where to Go from Here

With all the flexibility inherent in the *For Dummies* format, where should you start? If you know that you want information about a specific topic (for example, reverse mortgages or advance directives), by all means use the table of contents and index to find those sections. If you’re still getting your head around the idea of making long-range plans, pick a chapter that interests you and dig in. You don’t even have to start at the beginning of that chapter. But remember what Maria in *The Sound of Music* told her young pupils: The beginning is a very good place to start.

1

Getting Started with Navigating Your Later Years

IN THIS PART . . .

Find out how planning for your future yet staying flexible can help you stay in control and avoid crises.

Start assessing your current and future needs by creating a personal inventory of your health status, family and friends, personality characteristics, and attitudes about money. All these factors affect your plans, and some may make you think more deeply about your own preferences and values. You can also draw a CareMap, as shown in Chapter 2.

Start researching your options through federal resources, state and local resources, and private groups. Being inquisitive but skeptical is a good approach.

Make decisions a family affair. I suggest when a family meeting may be advisable, whether you need to invite an outside mediator, and how to avoid or deal with conflict.

IN THIS CHAPTER

- » Planning now for what you may need in the future
- » Overcoming potential roadblocks
- » Clarifying terms, options, and needs
- » Selecting good advisers

Chapter **1**

Looking Ahead: The Big Picture

Just by opening this book, you have become a member of a select group of people who are taking a big step toward a better future for yourself and your family. Most studies show that only a third of Americans have made even the most basic plans to prepare or pay for their future needs. Studies show that few older Americans have done substantial planning or saving for their future needs.

Thinking about the many aspects to consider — from finances to housing to healthcare and more — may be challenging because the choices available are often complex. They may involve myriad financial calculations as well as personal and family preferences. But planning today lets you envision the tomorrow of your choice and make it happen. In this chapter, I help you start to think about future needs in a proactive, calm, and positive way.

Planning for the Future Starts with You



REMEMBER

Future care is different for each individual, tailored to a person's needs and preferences. I want to reinforce this notion: Your plans today do not start with a place or a payment mechanism or a set of services; they start with a person.

Throughout this book, I reinforce the idea that a future plan is not just about where you live or what services you get but also about how you want to live and how to achieve your goals.

In addition to being person-centered, planning should start early. You'll want to start to think about housing, for instance, at a point when you have various options — whether at home or in a community — that prolong independence and make it less likely that institutional care will later be needed. From that perspective, modifying, and downsizing your home to make it safer and more accessible may be part of your plan. So is considering the possibility of multigenerational living and various forms of group residence in the community. Transportation options are critical to the success of your plan. These options are discussed in Part 2.

The chapters in Part 3 take up the important issues of financial and legal planning. What will Medicare pay for? What are the eligibility criteria for Medicaid? Should you consider buying long-term care insurance? What new products are available to meet financial needs? What steps can you take to draw up a will and other legal documents when you are healthy and able to make your preferences known?

Part 4 addresses managing your healthcare, from choosing a doctor to understanding different types of home care to the changes in skilled nursing facilities that are making these facilities more home-like and person-centered.

Part 5 looks at the special issues you may face if you are LGBT, a family caregiver, or a veteran of military service.

Finally, Part 6 has a chapter on common myths about aging and care. Here you'll also find a list of websites with state-by-state information, valuable because so much of future care is determined by state, not federal policies. Appendix A is a glossary of terms you may encounter, and Appendix B is a list of resources.

Navigating the Roadblocks of Planning

Aging is a reality. And an undeniable part of that reality is that most people, especially those who live to an advanced age, will need assistance in some aspects of their lives. If you are 65, you have nearly a 70 percent chance of needing some type of extended care and support at some future point, according to the U.S. Department of Health and Human Services. One-third of 65-year-olds may never need it, but 20 percent will need it for more than 5 years.

Yet what is undeniable in terms of demographics is easily deniable when it comes to anticipating our own lives and those of our older family members. About half of Americans over the age of 40 believe that “almost everyone” is likely to require long-term care at some point, but only a quarter think they themselves will need it, according to a 2016 survey conducted by the Associated Press–NORC Center for Public Affairs Research.

I can check off quite a few reasons for delaying the planning process, but there are just as many benefits to starting now.

Reasons for resistance

It isn’t hard to understand why we resist planning for our future needs. The usual suspects are societal attitudes that glamorize youth, attempts to erase signs of aging, denial of mortality, and fear of dependence.

Another reason for resistance to planning is the high financial cost, which is usually described in terms of skilled nursing facilities or extensive home care services. Search the Internet for “long-term care” and you will be directed primarily to articles on its financial aspects, offering suggestions about financial planning or advertising facilities and services. Paying for long-term care is a major topic (and it comes up repeatedly in this book; check out Part 3), but it is by no means the only topic to consider. Sometimes the focus on the high cost is itself a deterrent to planning. It may seem impossible to save or obtain that much money, so why try? Again, costs are a reality but should not deter planning.



WARNING

Only about a third (35 percent) of the respondents in the AP–NORC survey I cite earlier had saved money to pay for their long-term needs. Moreover, their understanding of costs was wide of the mark, both in underestimates and overestimates. Under a third can correctly identify the range of costs for nursing homes, assisted living, and home care aides. And they didn’t expect to pay the bill themselves. They expected Medicare to pay for a home health aide or a nursing-home stay, which is covered only for short-term care, not long-term care, and then only under certain circumstances. (For more on what Medicare covers, see Chapter 11.)

The benefits of planning

Decisions made in a crisis are often hasty and ill-considered. This is true in many aspects of life but is particularly problematic when a person’s health and well-being are at stake. Not all crises can be avoided, but when they do occur, having a plan in place reduces the likelihood of the most severe unintended consequences.

For example, an important part of a plan is having an advance directive and identifying a healthcare proxy (a person legally authorized to speak for you; see Chapter 17 for more information). In a medical emergency where you can't speak for yourself, an advance directive and a healthcare proxy can make it more likely that you get the types of treatment you want and — even more difficult to achieve — don't get what you don't want. Certainly, it can be hard to think about this kind of situation, but the alternative is worse. Without some form of advance directive, no one will know what you want or don't want, and it will be unclear who has the authority to speak for you. If your family members can't agree, the decision will be made by strangers, and in the worst-case scenario, there will be litigation. The effort involved in planning ahead is minimal compared to the consequences of not doing so.

This example also underscores another benefit of planning: making decisions for yourself instead of leaving them to others or to chance. Having absolute control is unrealistic and possibly even undesirable, but letting family and other intimates know your values and preferences about treatment goals leaves more in your hands.

Some families are used to discussing and even arguing about all sorts of things, from trivial to significant. Others avoid conversations about serious matters. You can't change family dynamics that developed over years, but you can work within that framework to make your wishes known and to anticipate objections. Sometimes you may have to make some compromises, such as limiting when and where you drive or accepting some help at home. In other situations, your family may have to accept a less-than-perfect living situation out of respect for your wishes, such as staying in your own home. If you and your family can negotiate these bumps, you are all less likely to find yourselves in opposite camps when it comes to making major decisions.



REMEMBER

Planning ahead also allows you to investigate more choices more thoroughly. You will still have hard decisions to make, but you will have the benefit of information, discussion, and time. Still, your planning should be flexible. Try to build in as many alternatives as possible to allow for changes in health, finances, family situations, and all the other elements that can make a difference.

Unraveling the Meaning of Long-Term Care

Although I use it sparingly in this book, you've probably heard the phrase *long-term care*. This phrase, still used throughout much of the field of aging and health-care, is not straightforward. Many people in the field of aging consider long-term

care to be services that are nonmedical, such as personal care (bathing, dressing, feeding) or household tasks (shopping, cooking, transportation). Although these aspects of assistance are essential, in this book I take a broader view to include factors like medical care, housing options, financial considerations, advance care planning, and the community environment. I believe that when considering future care, most people should look at the whole spectrum of need rather than only specific segments.



TIP

A good introduction to the basics of long-term care is this government publication: longtermcare.acl.gov/the-basics/.



TECHNICAL
STUFF

The National Center for Health Statistics found that about 67,000 long-term care providers served about 9 million people in the United States in 2013–2014. These included 30,200 assisted-living and other residential care communities, 15,600 nursing homes, 12,400 home health agencies, 4,800 adult day services, and 4,000 hospices. The majority of home healthcare agencies, hospices, nursing homes, and assisted-living and other residential care communities were run by for-profit companies, often affiliated with chains. Only adult day services were mostly non-profit. It's a myth that most older adults are in nursing facilities: the actual number is about 1.4 million out of a total population of 47.8 million over the age of 65. The full report is available at www.cdc.gov/nchs/data/series/sr_03/sr03_038.pdf.



REMEMBER

As I frame it, long-term or future care includes the various kinds of assistance a person needs to maintain the highest possible level of health and quality of life over time. As the population ages and increasingly more people face chronic illnesses, which often diminish the ability to function independently, future care needs to encompass and integrate a broader range of services to meet complex needs. Some aspects of planning concern immediate or foreseeable needs — for example, for a person with chronic illnesses or disabilities. Other aspects may fall under the heading of long-range planning — for example, considering long-term care insurance or establishing a regular savings plan. Some aspects of planning, such as preparing a will and an advance directive, should be done by every adult, even those in excellent health.

Defining long-term services and supports

One term you may run across as you plan for the future is *long-term services and supports*, or LTSS. This term typically refers to nonmedical services paid for privately or by Medicaid, although it can also apply to services such as transportation and homemaker visits provided by community agencies. By replacing the *care* in *long-term care* — which some people with disabilities see as a negative term — with the more impersonal *supports and services*, the new terminology is intended to stress an individual's independence and control over who helps and how that assistance is organized. Whichever term is used, a person- and family-centered approach is key, and this is something I stress throughout this book.

Noting that “LTSS has traditionally been provided in a fragmented, uncoordinated system of care provided by disparate agencies, each with its own funding, rules, and processes, and which are separate from the healthcare system,” the federal Commission on Long-Term Care in its 2013 report to Congress recommended that individuals and service providers “align incentives to improve the integration of LTSS with healthcare services in a person- and family-centered approach.” The Commission’s final report is available at www.gpo.gov/fdsys/pkg/GPO-LTCCOMMISSION/pdf/GPO-LTCCOMMISSION.pdf. While some states and localities have taken steps to achieve this goal, it remains unfulfilled for many people.

Understanding what Medicare covers

“Medicare does not cover long-term care.” You’ll probably come across this mantra again and again in your research. Yet in this book I devote considerable attention to Medicare, precisely because many beneficiaries consider it their starting point in thinking about their future care needs. So, what will Medicare cover? Understanding its limits is a first step in your reality check. What Medicare covers (after deductibles, coinsurance, and copays), you do not have to pay for; what Medicare does not cover requires additional resources.

To help you understand what Medicare covers, here is its definition of long-term care, as stated in its 2018 handbook “Medicare and You”:

Long-term care includes nonmedical care for people who have a chronic illness or disability. This includes nonskilled personal care assistance, like help with everyday activities, including dress, bathing, and using the bathroom. **Medicare and most health insurance plans, including the Medicare Supplement Insurance Plans (Medigap) policies, don’t pay for this type of care, sometimes called “custodial care.”** Long-term care can be provided at home, in the community, or in various other types of facilities, including nursing homes and assisted-living facilities.

And here’s Medicare’s definition of custodial care:

Nonskilled personal care, such as help with activities of daily living like bathing, dressing, eating, getting in or out of a bed or chair, moving around, and using the bathroom. It may also include the kind of health-related care that most people do themselves, like using eye drops. In most cases, Medicare doesn’t pay for custodial care.

Custodial care, a term many people find demeaning, is often called *personal care*. Whatever term you use, personal care does require considerable skill, as anyone who has performed these tasks knows.