Chapter 1

Looking Ahead: The Big Picture

In This Chapter

- Defining long-term care broadly
- Seeing the changes and new options
- Selecting good advisors

Just by opening this chapter, 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 for their future care needs. Perhaps you are already facing this dilemma for an aging or sick parent who lacks a plan for the long term and so you know how important it is to consider the future.

Thinking about the many aspects to consider — from finances to health to housing to more — is emotionally difficult, but it is also intellectually challenging because the choices available are often not clear-cut. They may involve complex financial calculations as well as personal and family preferences. But ignoring the question only makes the day of reckoning that much more difficult. In this chapter I help you start to think about long-term care in a proactive and positive way.

Planning for the Long Term Starts with You

Long-term care is different for each individual and ideally should be tailored to a person's needs and preferences. I want to reinforce this notion: Long-term care does not start with a place or a payment mechanism or a set of services; it starts with a person.

Many conventional definitions, however, start with a different focus — what services are included, who provides them, where they are provided, and, most important, who pays (or won't pay) the bill. These factors are obviously important, but they should not overshadow the person at its center.

In addition to being person-centered, planning should start early — at a point when various options for living at home or in a community can be arranged that prolong independence and make it less likely that institutional care will be needed. From that perspective, modifying your home to make it safer and more accessible is part of a long-term care plan. So is considering the possibility of multigenerational living and various forms of group residence in the community. These options are discussed in Part II.

The chapters in Part III take up the important issue of paying for care. Coordinating one's healthcare needs with other kinds of assistance is a critical element because staying healthy is a good way to avoid the need for heavy-duty long-term care, and these topics are discussed in Part IV. Finally, Part V looks at the special issues you may face if you're part of a specific group, such as family caregivers or veterans of military service. Part VI has a chapter on common myths about aging and long-term care and one on using websites with state-by-state information, valuable because so much of long-term 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. Throughout this book I reinforce the idea that a long-term care plan is not just about where you live or what services you get but about how you want to live and how to achieve your goals.

What Is Long-Term Care?

Defining long-term care is, perhaps surprisingly, 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 long-term care, most people should look at the whole spectrum of need rather than only specific segments.

In its 2013 overview of long-term care service providers, the National Center for Health Statistics found that about 58,500 providers served about 8 million people in the United States. These included 4,800 adult day services, 12,200 home health agencies, 3,700 hospices, 15,700 nursing homes, and 22,200 assisted living and other residential care communities. The majority in four of

these five sectors were for-profit organizations. Only adult day services were mostly nonprofit. While these numbers may seem large, they do not include the family caregivers who provide unpaid care to the vast majority of older adults who need long-term assistance. The full report is available at http://www.cdc.gov/nchs/data/nsltcp/long_term_care_services_2013.pdf.

As I frame it, long-term 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, long-term 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 might 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 advance directive, should be done by everyone, even those in excellent health.

Looking at long-term services and supports

As an alternative to the term *long-term care,* another term has entered the lexicon: *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 *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 provides assistance and how it is organized. Whichever term is used, a person- and family-centered approach is key, and this is something I stress throughout the 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 the 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 http://ltccommission.lmp01.lucidus.net/wp-content/uploads/2013/12/Commission-on-Long-Term-Care-Final-Report-9-26-13.pdf.)

In this book, I have chosen to use *long-term care* as a general category and *long-term services and supports* when referring specifically to services called by that name.

Using Medicare as a starting point

"Medicare does not cover long-term care." You'll come across this mantra again and again as you research long-term care. Yet 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 reality testing. What Medicare covers (after deductibles, coinsurance, and copays), you do not have to pay for; what Medicare does not cover requires additional resources.

Here is Medicare's definition of long-term care, as stated in its 2014 handbook "Medicare and You":

> *Long-term care: —A variety of services that help people with their medical and non-medical needs over a period of time. 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. Most long-term care is custodial care. Medicare doesn't pay for this type of care if this is the only kind of care you need.*

Note the final "if" clause; this creates an opening for custodial care when the person also has a need for skilled care.

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

> *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,* but it means the same thing. And it is definitely not *nonskilled*, as anyone who has performed these tasks knows.

Navigating the Roadblocks

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. The Kaiser Family Foundation estimates that 70 percent of Americans 65 and older will eventually need assistance for an average of three years.

Yet what is undeniable in terms of demographics is easily deniable when it comes to our own lives and those of our older family members. A study conducted by the Associated Press-NORC Center for Public Affairs Research in 2013 found that 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.

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

Reasons for resistance

It isn't hard to understand why there is so much resistance to thinking about care for the long term. The usual suspects are societal attitudes that glamorize youth and promote ways to erase signs of aging, denial of mortality, fear of dependence, and other anxieties.

Another reason for resistance to planning is the high cost of long-term care, which is usually described in terms of nursing homes or extensive home care services. Search the Internet for "long-term care" and you will be directed primarily to articles on its financial aspects, written by business writers and offering suggestions about financial planning. Paying for long-term care is a major topic (and it comes up over and over again in this book; check out the chapters in Part III), but it is by no means the only topic to consider. Sometimes the focus on the high cost is in 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.

Only about a third (35 percent) of the respondents in the AP-NORC survey I cited earlier had saved money to pay for long-term care. Moreover, their understanding of costs was wide of the mark, both in underestimates and overestimates. Under a third were able to 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, not long-term care, and then only under certain circumstances. (For more on what Medicare covers, see Chapter 10.)

Benefits of planning

Decisions made in a crisis situation 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 an advance directive (see Chapter 16). In a medical emergency, if you can't speak for yourself, an advance directive and a healthcare proxy (a person legally authorized to speak for you) 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 can't agree, the decision will be made by strangers, and in the worst-case scenario, there will be litigation. The effort involved in creating an advance directive is minimal compared to the consequences of not having planned ahead.

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 long-term care is very important.

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 have taken years to develop, 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 your driving 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. 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.

Planning 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 has to 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.

How Care for the Long Term Is Changing

Long-term care isn't what it used to be — and that's a good thing. There are many more options for living at home or in the community, where the vast majority of people want to be. Technology is making it possible to have your

healthcare monitored at home and to keep you in touch with family and friends. There is a greater awareness of the importance of a stimulating environment for mental and physical health.

Nursing homes are changing too, as they move toward a more person-centered focus and introduce elements of stimulating activity and participation for their long-stay residents.

Looking at why changes are being made

There are several reasons for the changes in long-term care.

Money is a factor

One reason is economic: Medicaid — the federal-state program for low-income people — is the major payer of long-term care. According to a February 2013 report from the National Health Policy Forum, in fiscal year 2011 Medicaid paid 62.3 percent of long-term care expenditures, with 21.9 percent paid for out-of-pocket, 11.6 percent by other private sources, including long-term care insurance, and a small percentage (4.6 percent) by other public sources, such as the U.S. Department of Veteran Affairs (VA). The report is available at `http://nhpf.org/library/the-basics/Basics_LTSS_02-01-13.pdf`.

Medicaid's long-term care expenditures are expected to increase from $207.9 billion in 2010 to $346 billion in 2040. To keep this spending in check, Medicaid has tried to move away from what has been called an "institutional bias," which means that the bulk of funding goes toward nursing homes, putting it instead toward more community-based care. In 1995, for example, 80 percent of Medicaid spending on long-term care was for institutional care; by 2011 that percentage had dropped to 55 percent. Community-based care is typically cheaper than nursing home care, which makes it attractive to Medicaid programs faced with escalating costs, and is also preferred by individuals. While this should be a win-win situation, it has proven difficult to implement fully, partly because of the need for more housing options and direct-care workers to provide community care. Another reason is that federal rules require Medicaid programs to provide institutional care but home- and community-based services are optional.

Legal reasons

The federal Americans with Disabilities Act (ADA) is another reason for the change. In 1999, the U.S. Supreme Court held in *Olmstead v. L.C.* that unjustified segregation of persons with disabilities in nursing homes constitutes discrimination in violation of Title II of the ADA. The Court held that public programs such as Medicaid must offer community-based services to

persons with disabilities when such services are appropriate, the affected person doesn't oppose community-based treatment, and community-based services can be reasonably accommodated, taking into account the resources available and the needs of others who are receiving disability services from the entity.

In its ruling, the Supreme Court explained that "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable of or unworthy of participating in community life." Furthermore, "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment." Although the case that reached the Supreme Court was about two young people with mental disabilities, the *Olmstead* decision applies to people of all ages and all different kinds of disabilities. (Many states, including Georgia, the state where the plaintiffs in the *Olmstead* case lived, have yet to implement fully a plan for moving eligible people from institutions to the community.)

While the *Olmstead* ruling is limited to a defined group of nursing home residents, it acts as an incentive for federal and state programs to develop appropriate community-based alternatives to institutions, which may benefit a larger group of people. It also reaffirms the importance of consumer choice in long-term care.

People want change

In addition to economic incentives and legal rulings, consumer demand has also played a part in moving away from old forms of long-term care to more home-like and person-centered settings. As people live longer — often into their 90s and beyond — the length of time a person needs various forms of care has increased and has required accommodation to various levels of need.

Although the trends of longer lives and person-centered settings are positive, implementation across the country is inconsistent and variable. At best, the system is a patchwork quilt of settings and services, some strong and some weak, with different eligibility requirements and payment sources. But compared to a few decades ago, the quilt itself is bigger because people have demanded better options. In succeeding chapters I describe several of these newer options, with some suggestions about how to find out more about what is available in your community.

Keeping up with insider language

Every industry and service enterprise has its own language. Long-term care is no exception, and the terms are constantly evolving. Those who are fluent in this language sometimes forget that newcomers to the field don't understand their acronyms, short-hand, and jargon. Throughout the book I explain

terms as they come up, and I include a glossary in Appendix A. Just to get started, however, here are a few of the terms commonly used in the new world of long-term care that you may encounter. As you move forward, don't hesitate to ask when someone uses a term you don't understand or seems to be using a term in a way that is unfamiliar.

- **Activities of daily living** are ordinary tasks like bathing, eating, getting dressed, and going to the bathroom that most people don't think twice about but that become difficult for a person who is ill or has a disability. Assistance with ADLs can range from lending a hand, literally or figuratively, to heavy lifting and total responsibility for carrying out the task. (Also see IADLs later in this list.) The number of ADLs is often used as a benchmark for eligibility for long-term care insurance benefits or nursing home or home-based services.
- **Acute care:** The type of care provided in hospitals to treat an illness or accident that needs immediate attention. Acute care is distinguished from *chronic care,* which treats illness that last for a long time, and *long-term care,* which may involve episodes of both acute care and chronic care. Coordinating care among acute care and chronic and long-term care is often a job that falls to family members or to the person needing the care.
- **Assisted-living facilities (ALFs):** Even though most people have heard of assisted living, there is no standard definition. States vary in what they call these facilities and how they regulate them, if they do at all. Generally, however, assisted-living facilities are group settings for people who need assistance in ADLs or IADLs but do not require nursing home level medical care. (See Chapter 6.)
- **Instrumental activities of daily living (IADLs):** These activities are the common household or management tasks such as paying bills, organizing transportation, shopping, laundry, and the like. They often go hand in hand with ADLs because the person who needs assistance with physical care may not be able to drive or shop alone. Even using the phone with all the complicated prompts that one encounters today may be difficult for someone with, for example, severe arthritis. But needing assistance with ADLs or IADLs is not necessarily associated with cognitive decline.
- **Skilled nursing facility (SNF):** A nursing home that can provide skilled nursing care that can only be provided by a nurse, such as injections, and rehabilitation services, such as physical therapy, and is certified to meet federal and state standards.
- **Transfer:** Here's a term that has several meanings. In long-term care jargon, it usually means moving a person from bed to chair or the reverse. Someone who is a *two-person transfer* requires not just one but two aides to do the job. This may be because the person is obese, paralyzed, or has another condition that makes it unsafe for both person and helper to manage alone. The second meaning of *transfer* refers to moving a person from one setting to another, such as from an assisted-living facility to an emergency department.

A good place to look up terms that relate to Medicaid and financial issues is the glossary at http://longtermcare.gov/the-basics/glossary/. Another resource is the United Hospital Fund's Next Step in Care "Terms and Definitions" at www.nextstepincare.org/Terms_and_Definitions/. For medical terms, consult a medical dictionary such as Medline Plus at www.nlm.nih.gov/medlineplus/ from the National Institutes of Health.

You will find that different people interpret terms differently and that agencies and insurance companies often have their own interpretations of what counts as, for example, *medically necessary,* which is often the trigger for benefits. To keep everything straight, I suggest that writing down the information you're given when it relates to eligibility or another aspect of services along, with the name, title, and contact information of the person who gave you the information. And if you don't like the definition you're given by someone, you may be able to get a more favorable interpretation from a supervisor after you've explained the situation.

Meeting Your Changing Needs

Long-term care is, or should be, a dynamic process. The needs of a person with mild cognitive impairment, for instance, are very different from the needs of a person with advanced dementia. As another example, someone diagnosed with diabetes needs chronic care, that is, doctor or nurse visits, ongoing monitoring, including blood tests, medications, and foot and vision exams. If the diabetic condition deteriorates to the point where the person is unable to walk or perform daily activities independently, then long-term care needs come into the picture. Someone considering moving from house to apartment or assisted living should think about whether this is a move that can satisfy future needs as well as immediate ones. Not everyone moves though the spectrum of needs at the same pace, or even goes through all the same stages.

Some future needs can be anticipated, and others cannot. The goal is not to have a detailed plan for every possible contingency but a general idea of what can reasonably be anticipated and planned for.

Location, location, location

The well-worn real estate adage of choosing a home on the basis of location applies to long-term care as well. In this case, location is not so much an economic asset (although in some cases it can be) as a symbol of personal

comfort and satisfaction. Long-term care is not just about services and providers; it is primarily about meeting all your needs, and that includes the social and emotional aspects.

Many people just say, "I want to stay in my own home!" And indeed, that's a reasonable short-term goal, but it may not be feasible in the long run. Beyond their initial statement, many people just stop thinking about it, or assume that their children (or more likely, a particular child) will say, "I'll move in with you so you can stay at home." Maybe that will happen, and maybe it won't. But it certainly requires an explicit understanding between the parties, not just an assumption.

In thinking about location, you want to consider:

- **The pros and cons of relocation:** Moving to another community to be nearer children, often at their urging, is one solution. You have to consider what you may lose and what you may gain. Someone with strong ties to a particular community, for example, a faith community or club or other group, may miss that connection. On the other hand, you may be able to re-create those ties in another setting. A lot depends on the type of community you would move to, whether you have spent enough time there to be confident you would like it, and whether you will have to depend on your children for transportation and other needs. Being a visitor and being involved in their activities is different from being a permanent resident. Some social groups welcome newcomers, but others closed their ranks a long time ago.
- **Climate:** It's almost a stereotype that older people want to move to warmer places, but in fact that is one main reason people do relocate. There may be health reasons to move to a different climate, or the upkeep on house and car in a winter zone may be too onerous to sustain. But not everyone adjusts easily to a more or less constant temperature, especially if it's very hot. And although blizzards can create dangerous situations for someone living alone, so can hurricanes and tornados, which generally occur in warmer areas.
- **Cost of living:** Different regions of the country are more or less expensive places to live. This applies not only to independent or assisted living but also to costs of medical care, food, personal-care services, transportation, and other items that will figure into your plan.

An extended visit to a community you are considering is a good way to find out whether you like it or not. Before or after your visit, you can look online to get an idea of prices for everything from groceries to rentals. You will also see what social, sporting, and cultural events are featured. Think about what you most like to do now and what you would like to be able to do in a new location.

Timing and flexibility

If you are going to make a change, when is the best time to do it? I can't give you the perfect answer. Still, if you are planning to stay where you are for the immediate future, you should start now reassessing your home for safety and accessibility. The mostly minor modifications you can make now (see Chapter 5) will help prevent falls, which are the most common reason for a need for more intense long-term care services. Even if you don't expect to stay in this location permanently, the modifications will add value to your home because they will also make it safer for others, including families with young children.

At the same time, you should begin to investigate alternatives. Without the pressure of family members or doctors insisting that you make a change, you can think about what matters most to you and what you have become used to but can live without.

If a change does fit into your plan, allow enough time to make all the arrangements, and consider all the pieces that need to be reassembled in a new location, whether that is assisted living, a retirement community, or apartment. Moving is one of life's most stressful events, even if it is well-planned and desired. Take your time.

You may not have enough space in your new location for the lifetime of memorabilia or objects you have collected. You may have to donate or sell some possessions. If you are moving from a big house to a smaller house, apartment, or condo, you may have to decide what furniture to keep and what won't work in the new setting. This is a process that stops many people from moving forward, but if you enlist help from family and friends, and if need be, from professional organizers, it can be liberating.

Be flexible. Even if you aren't moving to a different location or a different community, you're entering a new stage of life. Change can be stimulating but also disorienting.

Paradoxically, remaining independent often means asking for help. Asking for and accepting help is often a major hurdle in any long-term care plan. Being willing to acknowledge that you can't do everything alone (and probably you never really did) is the first step toward a person-centered long-term care plan. Family and friends are your first sources of help but they are not the only ones. Neighbors, volunteers from community groups, building contractors, home care aides, and transportation services can all play a part in helping you achieve your goals.

Getting Professional Advice

Among the people you may need to consult in making long-term care plans are professionals such as doctors, lawyers, and accountants. These professionals can help you make realistic plans and avoid costly and potentially damaging errors.

Choosing these advisors can be tricky, however. Your niece who just graduated from law school may offer to help you write a will, but she lives in a different state and doesn't know the law in your state. You have some investments with a local broker, and you have done well with his recommendations. But he has a financial interest in guiding you toward certain choices, which may not serve you well as you contemplate a long-term care plan. And even your doctor, who has taken care of you for years, sees you as you are, not necessarily as you may become. She may or may not be the best person to give you a completely honest appraisal of your health outlook for the future.

All of these people may be competent advisors. It makes sense, however, to consult with others so that you can be sure you are getting objective and accurate information.

For example, you may want to ask for a special geriatric evaluation from a physician who is experienced in caring for older adults whose course of illness and reactions to medications may differ significantly from younger people. An attorney who specializes in elder law has seen the troubles people get into with carelessly written advance directives or wills and can guide you toward creating documents that contain the precise instructions you want. And a financial advisor who charges a fee but does not gain from your investment choices may be a good person to help work out the financial aspects of your plan.

When considering using the services of a specific professional, ask about the following issues before moving forward:

- Experience with working with clients with similar needs
- Length of time in practice
- Recommendations
- Fees for the service

Even with good advisors, you need to be intimately involved in all decisions (or have a family member do this on your behalf). The investment of your time and money helps ensure that you get the kind of care for the long term you want.