Chapter 1 Elder Care Needs

Elder Care Needs and Services
A quality elder care plan will be concerned with quality of life for the older client's remaining lifespan, which could be a few months or even three decades.

One task of the family members and professional advisors involved in the planning team is to make sure that the pension and other post-retirement funds are chosen and deployed wisely. But that is not the end of the story. People over 65 vary greatly in their physical and mental capacities and needs. Some need a few more nice days to perfect their golf swing, while others need constant hands-on care to perform even the most basic tasks of survival.

Health care is fairly peripheral to most financial plans, but it is crucial and central to elder care plans. With luck, very little medical care will be required and whatever care is necessary will be fully covered by Medicare and Medigap insurance. Yet, for many senior citizens, Alzheimer's disease or some other type of dementia will cause a gradual, but eventually severe, loss of cognitive power and ability for self-care. Or a chronic illness or a combination of several illnesses and conditions will call for home care assistance, a move to specialized housing, or a move to a nursing home.

Therefore, sound planning for the post-retirement years requires:

-A health care plan to ensure that quality care will be available when needed
-A way to pay for the care

Care mechanisms could include treatment by physicians, hospitalization, skilled or custodial nursing homes, care at home, or a move from the community to specialized housing. Payment sources might include the retiree's own funds, contributions by family members, an employer's health plan, Medicare, Medigap insurance, long-term care insurance, or Medicaid. More to the point, the plan will probably evolve over time, as the older person's needs change.

Deploying the Planning Tools
In many ways, sound planning remains the same no matter the age or medical condition of the client. Certainly, the planner will want to make sure that the client can achieve lifestyle objectives: having the appropriate income level, taking reasonable planning steps to minimize the tax burden, and drafting any documents needed for transactions or transfers including trust documents and a valid will.

In many instances, financial planners work with married couples, or are consulted by a married man who takes the lead in planning for the family. One type of typical client is a mid-life male executive or professional. But elder planning also involves many clients who are widowed or who never married. The typical client might be the elderly widow. Many planning devices are tailored for married couples: for instance, the gift and estate tax marital deduction and Medicaid protection for the community spouse. Of course, if the client is widowed or never married these devices are inapplicable.

Good planning requires an unprejudiced mind set. It is most common that in a married couple the husband will be older, earn more, have more assets, become sick first, and die first, leading to a prolonged period of widowhood for his spouse. This assumption does not necessarily pan out in a particular case. The younger spouse may die first, leaving a spouse suffering one or more serious physical or cognitive problems. This spouse may nevertheless survive for many years, requiring a large and ever-increasing amount of care in each year.

Not every senior citizen suffers from mental incapacity, and some will never suffer diminished capacity. Do not forget that senior citizens, just like their younger counterparts, are entitled to express generosity and romantic feelings. They are allowed to make mistakes about relationships or investments, as long as they are not the victims of illness, fraud, duress, undue influence, or financial elder abuse.

Alzheimer's Disease

In January, 1998, the GAO estimated that in 1995, at least 1.9 million, and probably closer to 2.1 million American senior citizens suffered from Alzheimer's disease at some level of severity. The prevalence increased greatly with age for those between 65 and 85, doubling every five years until leveling off at age 85.

The Alzheimer's Association estimates that the economic impact of this tragic disease is at least $33 billion a year. That is just the cost to business, as distinct from the Medicaid costs and out-of-pocket costs of caring for people with dementia. The Association's estimate is higher than GAO's. The Association believes that there are about four million Alzheimer's sufferers in the United States, that at least 19 million people have a family member with Alzheimer's, and that 90 percent of Alzheimer's patients have a family member who provides care giving assistance.

Although some caregivers are forced to quit their jobs or shift to a part-time schedule to meet their care giving obligations, about four-fifths of employed caregivers work full-time. About $26 billion of the cost to business comes from lost productivity among caregivers absent from work to cope with family needs. Replacing caregivers who are forced to quit their jobs costs the economy over $3.5 billion. An estimated $1.3 billion is allocated to keeping up health insurance for caregiver-employees who take leave under the Family and Medical Leave Act, to heavy usage of Employee Assistance Programs by caregivers, and to fees for temporary agencies. Industry also spends an estimated $7.14 billion on health insurance and taxes that are allocated to senior citizens' health care and federal Alzheimer's disease research.

It should be noted that Alzheimer's is not the only source of mental confusion among the aging. Problems can be caused by depression which often responds well to medication, hardening of the cerebral arteries, strokes, or adverse reactions or over-concentration of medications. There are an increasing number of programs for Alzheimer's patients, including day care centers and specialized housing and nursing units that provide stimulation and calm agitation. These programs make it possible for Alzheimer's patients to use energy safely without wandering and getting lost.

Care Needs

As it stands now, Baby Boomers are doing the bulk of the care giving, but eventually they will be

senior citizens and in need of care. In 1995, long-term care for the elderly cost over $90 billion. Medicare and Medicaid paid 60 percent of those costs, while most of the rest came out of the pockets of the elderly and their families. In 1995, long-term care insurance paid less than one percent of the total bill for long-term care. As the size of the senior population increases, and as health care continues to become more expensive, the overall bill for long-term care can only increase (as well as the productivity impact of younger relatives providing unpaid care). In 1998, close to one-quarter of the elderly population (at that time, more than 7 million people fell into this category) needed assistance with daily activities. The aging of the Baby Boomers could double or even quadruple the eventual number of disabled elderly people who need care.

It is hard to estimate exactly who will need nursing home care, and when they will need such care. In fact, it is hard even to find comprehensive data about actual nursing home utilization. However, once a decade, the federal Department of Health and Human Services performs a comprehensive nationwide survey. The latest survey was done in 1995, and it took until 1997 to compile and analyze the results.

In the decade between 1985 and 1995, the number of nursing homes actually declined due to the shift toward larger nursing homes (many of them owned by health-care chains). Between 1985 and 1995, the number of nursing home beds increased nine percent, but the number of nursing homes decreased 13 percent. In 1995, there were about 1.8 million beds in 16,700 nursing homes with 1.5 million beds occupied. Thus, nursing homes were full but not over-full (87 percent of capacity).

Close to 90 percent of nursing home residents were at least 65 years old with younger resident's victims of accidents or disease preventing their living independently. More than a third of nursing home residents were aged 85 or older. Close to three-quarters (72 percent) of residents were female. About one-sixth of residents were married. To look at it another way, Medicaid's provisions for the financial protection of the healthy spouses of nursing home residents are actually applicable to only about one-sixth of nursing home residents. Of the rest, 66 percent are widowed, 5.5 percent are divorced or separated, and 11.1 percent never married.

Caregiver Issues

The term "caregiver" is usually used to describe a family member or friend who provides informal, unpaid care. Caregivers differ in the amount of care they provide. Some live in the same home as the person receiving the care, and are responsible for significant amounts of hands-on care. Others, especially those who live far away, have a role that may include emotional and financial participation but not hands-on care.

The typical caregiver is a middle-aged woman caring for her aged mother. Caregivers are sometimes described as part of the Sandwich Generation because they are caught between the needs of their parents, their spouses, and their children. Care giving is emotionally stressful and often physically difficult. It limits the caregiver's productivity at work if the caregiver is employed. It may require the caregiver to quit a job or to cut back hours. For these reasons it imperils the caregiver's own financial security and ability to save for retirement.

Caregivers should be aware that a federal statute, the Family and Medical Leave Act (FMLA),

requires employers to grant up to 12 weeks unpaid leave per year (including full and partial days off) so that caregivers can deal with a parent's serious medical condition. It should be noted that the federal FMLA does not require employers to grant leave to care for a parent-in-law, although many caregivers are responsible for a mother-in-law or father-in-law. Many of the states have their own family leave acts, which may be more generous toward "caregivers-in-law."

In many cases, the caregiver will also serve as an agent under a Durable Power of Attorney, as trustee, or will be appointed as guardian for a mentally incapacitated senior citizen. The caregiver may also be named on the older person's joint accounts. Documents should set out exactly what powers the caregiver will have over the older person's finances, especially with regard to gifts. In some cases, "self-gifts" (gifts made by a caregiver to himself or to his spouse or children) are appropriate when they carry out the wishes of the older person and satisfy legitimate planning objectives, such as reducing the taxable estate. But in other instances they may be inappropriate, unfair to other family members, or possibly illegal as a violation of fiduciary responsibility.

End of Life Issues

It can confidently be predicted that all clients will die, sooner or later, as a result of one cause or another. Although nothing can alter this basic fact of existence, good planning can do a great deal to enhance the quality of life in the client's later years, including the time when the client is terminally ill or otherwise incapacitated.

The basic premise of our medical and legal systems is that health care is rendered based on a contract between the health care provider and the consenting patient. This model often breaks down at the end of life, because the patient is unconscious, suffers from Alzheimer's Disease or another illness that impairs cognition, or is otherwise unable to make care choices or give informed consent to care.

The legal system has responded in several ways, principally by making provisions for Advance Directives. That is, an adult who has mental capacity signs a document expressing his treatment wishes under various circumstances. The document can then be consulted if and when the patient is unable to express wishes directly. There are two main kinds of Advance Directives: the Living Will and the Durable Power of Attorney for Health Care. The Durable Power of Attorney for Health Care is also known as a health care proxy.

The Living Will is a written expression of the person's desire that treatment be either terminated or continued in the event the person ever becomes terminally ill and unconscious, or otherwise unable to express treatment preferences. States differ in the extent to which Living Wills can be used to refuse care or direct that nutrition and hydration be provided if the person is also unable to eat. Most states do allow Living Wills to be used for this purpose, as long as the person's wishes are clearly and unequivocally expressed. Also, an advance directive can be used to express a preference for maximum as well as minimum treatment.

The proxy works differently. It designates a person, such as a spouse, adult child, or family friend, to make treatment decisions if the patient cannot make the decisions personally. This is broader than the Living Will, because it can come into play when the person who granted the proxy is mentally incapacitated but not terminally ill. Once again, it is probably possible to give the proxy

decision-making power over nutrition and hydration decisions, but this is a matter of state law.

Certain health care providers that participate in Medicare, including hospitals and nursing homes, have an obligation under federal law to raise the subject of advance directives with their patients. The facility is not allowed to force patients to sign an advance directive. If a patient does sign an advance directive, the facility is required to make it a part of a patient's medical record. If a patient signs an advance directive, the health care provider is not required to provide care that conflicts with the advance directive. The health care provider is not required to implement an advance directive if, as a matter of conscience, the provider cannot implement an advance directive and state law allows any health care provider or any agent of such provider to conscientiously object. An increasing number of states have laws dealing with Do Not Resuscitate (DNR) orders. DNRs make it possible for an individual to say that he does not want CPR to be performed if he suffers a heart attack or respiratory arrest. Even in states that do not have specific statutes, it is worthwhile to discuss with the attending physician whether or not a "No Code" order should be placed in the medical record. If state law permits "out of hospital" DNR orders, and this is the client's wish, then local ambulance and EMS services should be notified and given a copy of the order so they will not perform an unwanted resuscitation.

Another trend in state law is the creation of "surrogate decision-making" laws. These laws set out a hierarchy of people (usually, the spouse first, then if there is no spouse, an adult child, and so forth) who have a legal right to make medical decisions for an incapacitated patient who has not created an advance directive. Since the vast majority of people do not create advance directives, these statutes solve many problems. Without such a statute, the health care facility must obtain a court order appointing a guardian and then approach the guardian for permission to carry out non-emergency health procedures, which is a cumbersome drain on both medical and legal resources.

The Planning Process and Team

The optimum elder plan reflects the wishes of the senior citizen and family to the extent that these wishes can realistically be carried out. It provides for quality care in the optimum setting. It can also provide for different settings, as needs change, since needs typically increase rather than decrease. The plan balances strictly financial issues such as investment and tax planning against medical, social, and psychological needs. It deploys financial products and services, as well as health care products and services, to meet these objectives.

You would not expect the average senior citizen to have access to a single person who combines the skills and perspectives of half-a-dozen professionals. The obvious solution is to create a planning team, each of whose members brings a set of skills and a professional perspective to the project of creating and monitoring the elder plan.

Depending on the facts of the situation, the preferences of the elder and family, and the size and complexity of the plan, the team might include:

-An attorney, preferably an attorney with current information about elder law. Certain states have a program that allows an attorney to become a Certified Elder Law Attorney

(CELA). Becoming a CELA is evidence of commitment to elder law, and of having achieved status within the field, although there are fine elder law attorneys who are not CELAs

-An insurance professional

-A Geriatric Care Manager (GCM), usually trained in nursing or social work, with practical expertise not only with services available to the elderly, how to coordinate a service plan, and how to apply for public benefits, but also day-to-day knowledge of, and contacts with, local service providers

-An accountant to deal with tax and financial matters (e.g., valuation of a closely held business when the founder retires)

-A financial planner, whether fee- or product-based

-A broker or investment advisor or both (the number and qualifications of people involved depending on the size and complexity of the portfolio).

Forming the Team

Professional ethical standards mandate that not only must a professional avoid practicing professions for which he is not licensed, but he should suggest the involvement of other professionals whenever the professional encounters a situation that he is not trained or equipped to deal with.

It should be made clear to the client that he can assemble the team personally, but that the professional initially consulted is willing and able to make referral suggestions. Consult the various codes of ethics for the extent to which fees can be shared, or if referral fees are appropriate.) In many instances, the client will not be aware of the full scope of services available, or of the division of labor among professionals. (For example: Few people outside the elder planning community even know that GCMs exist, and of those who are aware of GCMs, even less know how to work with them effectively.

The planner will want to develop a network of other elder planning professionals to work together on complex projects and to make referrals for simple tasks that fall into only one professional domain. An excellent way to do this is by attending multi-disciplinary continuing education programs. Not only will this hone the planner's skills, the planner will be able to observe local members of other professions.

In fact, it makes sense for a planner to offer his services as a speaker at single-profession or multi-disciplinary seminars. He can also offer his own seminars (e.g., to employee groups, at senior centers, or to a congregation), because individuals who have seen the planner offering useful professional advice are more likely to want to retain his services or purchase financial products from him.

Standards for making referrals, or adding a person to the team the planner recommends, include:

-Where and when did the person obtain basic education about elder planning?

-How does he stay current on elder planning issues? (E.g., from continuing education programs, committee activities, reading journals and newsletters, consulting Web sites that deal with planning issues)

-If professional specialty or certification programs are available, has the person obtained certification?

-Is elder planning central to the person's professional practice, or is it an afterthought?

-Is he aware of the functions of other professions in the team, and does he know when to refer the case or bring in another team member?

-Is he aware of potential legal pitfalls (so he will not give dubious advice) and sensitive to Medicaid and tax consequences of transactions?

-How much time will the person have to devote to this case?

-Will the person handle the case personally or delegate it to assistants? If it is delegated, how knowledgeable and skillful are the assistants?

-Does the person belong to important professional associations? Some professional associations are about as intellectually fruitful as a fraternity party, but others offer a year-round program of services, publications, and continuing education. On the other hand, some people just are not joiners, or they need to spend money that would otherwise go to dues on building a library or automating their practice

-Is the person easy to work with, and comfortable with older people and their families? How is his equivalent of a doctor's "bedside manner?"

Continuing Education and Certification in Elder planning

Late 1998 and early 1999 were marked by the development of several programs to train and certify elder planners. These programs merit investigation. One or more may offer a planner insights, planning tools, and enhanced credibility in the market. The Institute of Elder Planning Studies offers the Certified Elder Planning Specialists (CEPS) designation, covering many of the planning issues discussed in this course. The SRM (Senior Risk Manager) designation covers financial planning for individuals aged 60 to 85, but focuses on psychological factors rather than technical Medicare, Medicaid, and long-term care insurance issues. The Certified in Long-term Care Program (CLTC) deals with aging issues, Medicaid, long-term care insurance, and ethical issues, among others. An American Association of Long-term Care Insurance and National Forum on Long-term Care have both been formed, and may provide their own certifications.

Ethical Issues

Consider that when an eldercare planner takes on an elder planning case he is working for the whole family. The plan that is created may have implications that carry on for generations. The classic ethical issue for elder planners is "who is the client?" In the ideal case, everyone is "on the same page" and agrees what should be done. In the real world, it is far more likely that there will be disagreements and hard choices will need to be made. For example: It may cost more for a frail senior citizen to be cared for at home (with three shifts of attendants, plus professional care) than in a nursing home. If home care continues for years, and little or none of the cost is reimbursed by Medicare or insurance, there probably will be less for the senior citizen's heirs to inherit. Similarly, the decision of whether to discontinue life support may be colored by financial as well as religious and compassion-related motives.

Sometimes the older-generation member gets greater tax benefits from a lifetime gift, but the potential gift recipient prefers an inheritance. Sometimes the potential recipient wants a gift now, but the potential donor wants to hang on to the money. If a son or daughter is named as agent under a Durable Power of Attorney, the question becomes whether the agent is allowed to make gifts of the senior citizen's money to himself or to his family, and how this will affect the rest of the family.

As can be seen, there can be many interests and many opinions involved in creating a plan. The planner must decide who the client is and whose interests he must protect in case of conflict. Sometimes it is necessary for individuals with seriously conflicting interests to have separate representatives, or at least to sign a waiver indicating that they are aware of the potential conflict but choose to have the same attorney, accountant, or other adviser. It also matters who writes the check to pay the fee if the planner is a fee-based planner. That person may technically be the client, even if the planner was hired to make a plan for someone else. No matter who is technically the client, make sure that the planner receives the honest, unbiased, and uninfluenced opinion of the senior citizen who is the subject of the plan. It is often necessary to remove the children and in-laws from the room, and perhaps repeat the inquiries several times to find out what the senior citizen wants and not just what he thinks the children or in-laws want, or what an ideally unselfish parent would want.

Check with an experienced elder law attorney, or the local government agency that protects the elderly, for clues for how to spot physical or financial elder abuse and the scope of the legal duty to report suspected abuse. Most state laws provide that professionals have a legal duty to report suspected abuse that they observe as part of their professional practice. These laws provide that there is no penalty for making a good-faith report that turns out to be unfounded.

Another important ethical issue is how to handle a client who definitely would benefit by a particular transaction but perhaps lacks legal capacity to engage in the transaction. It is possible to reassure yourself, by taking extra time and trouble, that the older person finally understands the transaction and gives informed consent to engaging in it. See if the family or attending physician can suggest times when the older person is especially alert. But if capacity is permanently lacking, then it may be necessary to have a guardian appointed, to use a Durable Power of Attorney already in existence, or to have a guardian appointed for the specific and limited purpose of carrying out the necessary transaction.

Psychological Issues

The families the planner meets in his elder planning efforts will certainly be facing up to hard facts. Many of them will be going through a crisis. That means that sometimes the planner sees people at far from their best. Elder planning puts us in touch with some very frightening realities: chronic illness, debilitation, and loss of physical and mental capacity, loss of independence, confrontation with death, and the loneliness and anguish of survivors. To be an effective elder planner, a planner will have to understand how this work will affect him psychologically. On the good side, he may be "adopted" as a surrogate child by a really nice family who is grateful for the help he can give them. He may become caught in a swirling maelstrom of emotions in a family who is still angry and resentful about decades-old, half-forgotten events. He may be blamed for things that are not his fault and that he is not able to change: that he cannot bring back a lonely widow's beloved husband, that he cannot reverse a lifetime of bad financial choices by drafting a few documents, or that he cannot cure an inoperable cancer or restore capacities eroded by Alzheimer's disease.

The planner must be able to separate his professional skills from feelings about clients. He will also have to be able to sort out feelings about his own family from feelings about his clients and their families.

Income Tax Issues

Under our current system, where there are few tax brackets and the brackets are fairly close together, there is not much significance to the fact that many people drop into a lower tax bracket after retirement. For most purposes, senior citizens face the same income tax planning issues as any other taxpayer. See the various substantive chapters for income tax issues of, for instance, Social Security benefits, annuities, and retirement planning.

Persons over 65 are entitled to have approximately $1,000 more income than non-senior citizens before the need to file an income tax return at all is triggered. A senior citizen is entitled to a larger standard deduction than a non-senior citizen; an additional enhancement to the standard deduction is available to those who are legally blind. (These additional standard deductions are reduced if the senior citizen can be claimed as someone else's dependent.)

Low-income persons over 65 (and persons who have retired because of a permanent and total disability) may also qualify for a tax credit under Internal Revenue Code Section 22. The maximum amount of the credit is $1,125. The maximum credit may be reduced by non-taxable pension and Social Security benefits, and is phased out at higher income levels. For a married couple filing jointly, where both spouses qualify for the credit, the phase-out level starts at an Adjusted Gross Income (AGI) of $10,000 and completely phases out at an AGI of $25,000. See IRS Publication 524 for details. (A credit reduces the actual amount of tax due, while a deduction reduces the amount of taxable income that is used to calculate tax liability.)

In some instances, the senior citizen is considered, for tax purposes, as a dependent of a caregiver child, or of several children who have combined to provide a "multiple support agreement" covering the senior citizen. Five tests are used to determine whether a deduction may be taken:

-Whether the elderly person lives in the taxpayer's home for the entire year, or is a relative of the taxpayer.

-The elderly person is either a U.S. citizen or a legal resident of the U.S. or a country contiguous to the U.S.

-The senior citizen's gross income does not exceed $2,800 (in 2000 -- this amount is indexed for inflation); non-taxable Social Security benefits are not counted in gross income

-The senior citizen does not file a joint return

-The taxpayer provides at least half of the senior citizen's support (or at least half of the senior citizen's support is provided under a multiple support agreement).

If there is a multiple support agreement, it should be drafted to specify which contributor will take advantage of deductions arising out of the senior citizen's dependent status. The taxpayer claiming the deductions must personally provide at least 10 percent of the senior citizen's support. Unmarried caregiver whose dependent parent lives in his household can pay taxes at head-of-household rates, which are lower than rates for single persons. Head-of-household status may also be claimed by an unmarried person who pays more than one-half the cost of maintaining a separate household in which the parent lives. The child is deemed to maintain the household even during the parent's health-related absences (e.g., while hospitalized).

A caregiver child can claim a medical-expense deduction for expenses actually paid on behalf of a dependent parent. Even if the child is not able to take a dependency deduction (because the parent's income is too high, or because the parent files a joint return), the child can claim a medical expense deduction for amounts paid toward the parent's medical expenses. If there is a multiple support agreement, only the child who is entitled to claim the dependency deduction is allowed to deduct the parents' medical expenses. Other contributors to the multiple support agreement cannot, even if they actually paid the expenses.

Of course, the parents' medical expenses can be deducted only if they were not reimbursed by insurance or otherwise, if they are legitimate medical expense deductions, and only to the extent that, in conjunction with all other medical expense deductions, they exceed 7.5 percent of the taxpayer's adjusted gross income.

Not all health-related expenses are deductible. Unreimbursed costs of prescription drugs and insulin are deductible, but costs of over-the-counter medications are not. If an individual enters a nursing home primarily in order to receive medical care, all of the costs (including those that substitute for ordinary living expenses) are deductible. But if the primary motive is the convenience of the resident and the resident's family, then only the portion of the bill that can be allocated to medical and nursing care is deductible; the portion allocable to room and board is not.

Under appropriate circumstances, long-term care insurance premiums may give rise to a tax

deduction. Long-term care insurance benefits can be received tax-free, within statutory limits. The same limits apply to accelerated death benefits or viatical settlements that are received by a chronically (but not terminally) ill person who applies the benefits to the costs of health care. Tax advantages are not available to a healthy elderly person who chooses to enter into a viatical settlement for purely financial reasons.

Long-Term Care Needs and Services

Long-term care is a very broad term that refers to a spectrum of services, support systems, and facilities that are designed to meet the ongoing medical, social, and personal needs of those who have functional disabilities. As such, it encompasses a wide range of demographics, services, and funding resources. The primary goals of long-term care are to help individuals maintain functionality and maximize independence.

Long-term care involves a variety of services that include medical and nonmedical care for people who have chronic illnesses, disabilities, or severe cognitive impairments that keep them from living independently. Long-term care helps meet both health and personal needs. Most long-term care provides assistance with support services—for example, the activities of daily living, like eating, dressing, and bathing. This type of care is provided at home, in the community, and in assisted living environments. Long-term care can also take the form of skilled care in nursing homes.

It is important to understand that the need for long-term care can surface at any age and that services can take the form of formal or informal arrangements. The adult long-term care population is diverse, much more encompassing than simply the elderly living in nursing homes. The non-elderly and persons living in the community also represent a large proportion of people requiring long-term care.

Defining the Need for LTC

Long-term care recipients may be of any age. Conditions that may lead to the need for long-term care include disability, mental decline or illness, AIDS, stroke, and simple frailty. The need for long-term care is primarily measured by assessing limitations in performing or managing tasks of daily living, including self-care and household tasks.

Obviously, the likelihood of receiving long-term care assistance increases with age. The aging of Americans will only increase the need for quality long-term care options. The growth in demand will be driven by increases in the numbers of elderly as a result of the aging of the baby boom generation and the trend toward increased longevity.

Projections from the U.S. Census Bureau indicate a rapid and extensive increase in the elderly population. In 2030, when all the baby boomers will be 65 and older, nearly one in five U.S. residents is expected to be 65 and older. This age group is projected to increase to 88.5 million in 2050, more than doubling the number in 2008 (38.7 million). Similarly, the 85 and older population is expected to more than triple, from 5.4 million to 19 million between 2008 and 2050. The number of people 85 years or older, nearly half of whom need assistance with everyday activities, will grow even faster.

Regardless of age, older people are more likely to receive long-term care at home or through community services rather than in nursing homes. Because the need for long-term care is expected to grow substantially in the future, this will place an ever-increasing strain on already burdened public and private financial resources.

Measuring Long-Term Care Needs

The need for long-term care services is measured in two ways. Activities of daily living (ADLs) are basic daily tasks. Instrumental activities of daily living (IADLs) are tasks necessary for independent living. Both serve as a measure of functional capacity. When a person's functional capacity is diminished because of physical or mental impairment and he or she requires help with daily tasks of living, the need for care may be in order.

Activities of daily living are the fundamentals of self-care and the very basic tasks of everyday life. These include:

-Eating
-Bathing
-Dressing
-Toileting
-Continence maintenance
-Transferring

Instrumental activities of daily livings are tasks necessary for independent community living. They reflect how an individual interacts with his or her environment. IADLs include such things as:

-Using the telephone
-Driving
-Shopping
-Preparing meals
-Light housework
-Taking medications
-Managing money

Functional ability is the foremost indicator of the need for long-term care. The inability to perform ADLs and IADLs is the primary index of functional disability.

Who Needs Long-Term Care?

People may suddenly need long-term care after a crisis occurs, but for many, the need develops gradually. Older individuals are the primary users of long-term services, because functional disability increases with age. In 2008, about 9 million Americans over the age of 65 required LTC services. By 2020, that number will increase to 12 million. However, while most people who need long-term care are 65 or older, such services can be necessary at any age. Forty percent of people currently receiving long-term care are adults 18 to 64 years old.

According to the U.S. Department of Health and Human Services, the risk of needing LTC is fairly high. About 70 percent of individuals over age 65 will require some type of long-term care

services during their lifetimes. Over 40 percent will need care in a nursing home for some period.

Factors that influence the risk of needing long-term care services include the following:

-Age—Risk generally increases with age.
-Marital status—Single people are more likely to need care from a paid provider.
-Gender—Women are more likely than men to need long-term care, because women tend to live longer.
-Lifestyle—Poor diet and exercise habits can increase the long-term care risk.
-Health and family history—A family history of poor health may increase the risk of needing long-term care.

From a medical standpoint and in absolute medical terms, long-term care is chronic care with the aim of management, control of symptoms, and maintenance of function. Chronic care differs from traditional acute care, which is medical care aimed at treating physical problems directly in an attempt to permanently cure or control them.

Long-term care may result to treat debilitating injuries (from a fall or other accident, for example), pulmonary and cardiovascular conditions, psychiatric disorders, kidney and liver malfunction, and similar problems. Degenerative conditions such as Parkinson's disease and rheumatoid arthritis can summon the need for long-term care services. Patients with prolonged illnesses—cancer or heart disease, for example—or who are recovering from a stroke or severe burns often require LTC.

Alzheimer's disease and other forms of dementia also contribute to the need for LTC and the growing population of LTC recipients. These conditions are characterized by the loss of or decline in memory and other cognitive abilities. Severe enough, they will interfere with daily life and one's ability to function independently. The number of Americans with Alzheimer's and other dementias is increasing every year because of the solid growth in the older population. This number will continue to increase as the baby boom generation ages. The Alzheimer's Association estimates that 10 million baby boomers will develop Alzheimer's disease in their lifetimes.

How and Where Long-Term Care Is Delivered

Long-term care needs encompass a wide range of medical and support services for individuals who lack some capacity for self-care and who are expected to need care for an extended period. The level of care required determines how and where the care is delivered.

Long-term care can be either "formal" or "informal." Unpaid care from friends and family is termed informal care. Formal care is furnished by nurses, home aides, homemakers and other paid providers.

The Long-Term Care Continuum

Long-term care can be thought of as a continuum of health and social services ranging from care at home via home health and homemaker services to services in the community, such as adult day care, to skilled care in nursing homes.

Necessary services may be either continuous or sporadic. Services are delivered for a certain period to those whose ability to function is limited. These functional disabilities may be temporary or permanent, mental or physical. Functional disabilities—that is, the inability to perform the activities of daily living—preclude a person from remaining independent. The inability to perform instrumental activities of daily living also prevents complete independence.

Home-Based Care

Most LTC recipients receive their care at home. The goal of home-based LTC services is to help individuals maintain their independence in familiar surroundings. Home-based services maximize all available resources—the home setting, available family members, volunteer and paid services, and financial resources.

Those receiving care generally prefer to remain in their homes for as long as possible. ADL needs can be met informally with the help of family members and friends, as well as formally through volunteers and homemaker services agencies.

Home-based services typically encompass the following:

-Non-medical personal care services, such as help with ADLs
-Homemaker services, which include help with tasks such as companion services, meal planning and preparation, shopping, light chores, bill-paying, transportation, and other IADLs
-Home health care services which are provided by home health aides, registered nurses, licensed practical nurses, social workers, physical therapists, and hospice organizations, typically under a care plan prescribed by a physician.

Despite substantial public and private spending for long-term care, families continue to provide the majority of long-term care services. These caregivers provide informal or unpaid care to family members of all ages. Typically, adult children provide this care to elderly parents, and spouses provide it to one another.

Community-Based Care and Services

Community-based services take place outside the home in the community. These services meet the need for periodic care or supervision. They also serve the very important function of providing social contact for those who are frequently home-bound.

Community-based services include the following:

-adult day service (ADS) programs, also referred to as adult day care, which provide, for several hours at a time, structured health and social support services, such as meals, recreation, and rehabilitative therapy in a group setting

-senior centers, which furnish services such as nutritional counseling, meals, health screenings, and recreational, social, and educational programs without the level of supervision found in adult day service programs

-care giver support programs, which provide respite from the stress and demands of care giving in the form of substitute caregivers and caregiver support groups.

Facility-Based Care and Services

Facility-based services come into play when it is time to consider alternate living arrangements. Many LTC recipients need only assisted living types of arrangements. Perhaps they don't have the option of home-based care or have exhausted their home-based care resources. Others have health issues serious enough to require the level of care offered by a skilled nursing facility. For the range of services to meet these needs, the following facility-based services are available:

-Congregate housing, also called senior retirement communities, is merely a housing option for elderly residents who can take care of themselves. The community typically provides a variety of social and recreational activities.

-Adult foster care programs are composed of families who volunteer to take into their homes an older person who needs some help with ADLs or IADLs. They provide a room and services such as laundry and cooked meals.

-Board and care homes, sometimes called residential care homes, are group living arrangements offering a home-like environment. They typically provide help with the activities of daily living, but they encourage residents to act independently. They do not offer medical care.

-Assisted living facilities, similar to apartment-like settings, are an option for those who require a limited level of assistance. Residents are not able to live independently, but they also do not require skilled nursing care. These facilities encourage residents to bring their own furniture and keepsakes to make their units feel like home.

-Skilled nursing facilities (SNFs) represent a level of care that requires the daily involvement of physicians and a skilled nursing or rehabilitation staff. SNFs provide care to elderly or disabled patients who need substantial, long-term assistance. Personal care, recreation, and rehabilitation are also provided here.

-Continuing care retirement communities (CCRCs) can be thought of as large campuses consisting of many types of facilities. Some residents require no special assistance and live very independently in separate housing. Those requiring a slightly greater degree of support are housed in assisted living facilities on the same campus, and skilled nursing facilities are available for residents who need skilled care. CCRCs generally offer long-term contracts that guarantee care and shelter for life. Residents move from one facility to another as their health needs change. Because of the scope of services provided in CCRCs, they are very expensive and beyond the means of those with low to moderate income and assets.

Levels of Long-Term Care

In addition to the long-term care continuum which considers where care is provided, we must also examine the levels of care available to LTC recipients. Again, the level of needed care is a determining factor for how and where the care will be delivered. The three primary levels of care

are custodial, intermediate, and skilled.

Custodial care
Custodial care primarily provides assistance with ADLs. It is designed to meet the personal needs (as opposed to medical needs) of the recipient. Custodial care is not skilled medical care or therapy and does not require the ongoing supervision of trained medical personnel. It is intended to maintain and support an existing level of well-being and to preserve health and prevent its further decline. Custodial care may be delivered in the home or in a residence facility and may be performed in conjunction with an overall program of skilled treatment. In the home, custodial care is provided primarily by family members or friends but can also be provided by other unlicensed individuals or licensed health aides. By far, custodial care is the dominant form of long-term care.

Intermediate care
Intermediate care, delivered in an intermediate care facility (ICF), is provided under a doctor's supervision but is not considered to be continuously medically necessary. It includes nursing and rehabilitative care required only part-time or occasionally and is performed by skilled practitioners. Intermediate care may be provided at home or in a facility, depending on the particular condition and the patient's overall health.

Skilled care
Skilled care is provided in a skilled nursing facility (SNF). Skilled care is continuously medically necessary. That is, it is around-the-clock nursing delivered by RNs, LVNs, or LPNs, and at least one supervising RN is present at all times. Skilled care consists of nursing care, therapy, and rehabilitation. It is a comparatively high level of nursing and medical care for those whose conditions require ongoing and close monitoring.

Improvements in the Delivery of Long-Term Care Services and Providers
Historically, there has always been a need for health care specific to the elderly and other vulnerable populations. In tenth century Britain, almshouses funded by charity were established to provide a place of residence for the poor, old, and distressed. By the 1900s, the colonial almshouse became the first institution in this country to resemble institutionalized management of care for the poor, elderly, and disabled.

The Foundation for Long-Term Care in the U.S.
In 1935, President Roosevelt acknowledged the needs of the elderly citizens with the establishment of Title I of the Social Security Act, called the Old Age Assistance (OAA) program. This program gave cash payments to poor elderly people, regardless of their work record, by providing a federal match of state old-age assistance payments. The significance of OAA in the history of long-term care is that it created the foundation for the Medicaid program, which has become the primary funding source for long-term care today.

OAA provided elderly individuals with a steady source of income, allowing them to better care for themselves. However, OAA stipends were meager and insufficient to adequately meet recipients' needs. Though it abolished the need for almshouses and the shame associated with the poverty that accompanied these institutions, OAA did not address the need for a setting for chronic care for the elderly and disabled. As a result, the development of home care and nursing homes

emerged throughout the 1930s to the 1960s, forming the foundation for long-term care services and providers as we know them today.

Since the passage of the Social Security Act in 1935, several policies have played roles in the growth of the long-term care industry and its enduring efforts to cope with the complex issues of cost and quality. In 1950, amendments to the act established standards of care through nursing home licensing requirements and supported the growth of the LTC industry through the authorization of vendor payments. The Hill-Burton Act in 1946 and its many amendments influenced the growth of the nursing home industry by sponsoring the creation of a modern health care infrastructure.

In 1965, the Medicare and Medicaid programs were created through amendments to the original Social Security Act. Medicare and Medicaid became significant for the nursing home industry with the enactment of the 1967 Moss Amendments, which authorized nursing homes to utilize the Medicaid program. In 1972, Public Law 92-603 introduced Medicaid to those receiving supplemental security income (SSI) payments. In general, states rely on SSI eligibility rules, established at the national level, as the basis for Medicaid eligibility.

The Introduction of Long-Term Care Insurance

Long-term care insurance policies were introduced in the 1970s. However, the concept of taking responsibility for providing for one's own care in the event of a chronic disease or disability through insurance did not take hold until the late 1980s and early 1990s when the aging baby boomer generation began to accept this reality.

Until this time, extended care options were pretty much limited to care at home by family or through institutionalization. In the 1980s and 1990s, other LTC options gradually emerged. Assisted living facilities were pioneered to meet the need for those whose care requirements fell somewhere in between needing help with one or two ADLs and skilled nursing care. Assisted living facilities became very popular, and many found themselves on waiting lists to get in. Around the same time, the homemaker and home health service industries took off, and innovative concepts such as graduated care and adult day care were introduced.

Unfortunately, traditional health insurance did not cover the expenses associated with these growing care options. Many were forced to sell their homes and deplete their resources to receive state aid. Consequently, long-term care insurance was developed.

The Evolution of Long-Term Care Policies

The first LTCI policies were nursing home-only policies. Developed in the 1970s and covering care delivered only in nursing homes, these were not the full benefit policies we know today. The next generation of policies came about in the 1980s, which acknowledged the need for home health care benefits. Consequently, at this time, citizens could choose either nursing home-only policies or home health care-only policies. The early 1990s saw policies combining coverage for home health care, community-provided services, assisted living, and skilled nursing care. These were called comprehensive policies, and they allowed policy holder's to elect where and how to apply their policy benefits. The original nursing home-only and home care-only policies became known as non-comprehensive policies. Today, most insurers offer only comprehensive policies. In fact, in

some states, non-comprehensive policies are prohibited by law.

Another factor that has contributed to the evolution of long-term care policies is a better understanding by insurance company underwriters and actuaries of the risk assumed when an LTCI contract is issued. Some of the earlier generations of LTCI policies were not priced adequately, the result of poor underwriting, overly optimistic interest rate assumptions, inaccurate cost projections, and unanticipated lapse rates. When the time came for insurers to begin paying benefits under their original LTCI policies—some of which had been sold 20 years earlier—it became apparent that underwriters and actuaries did not know at the time the policies were issued how much health care costs would increase. Clearly, many insurers had underestimated their exposures. While some insurers made good on their claims, others were not able to do so. Policyholders who had been making their payments for years were not able to collect full benefits. Other policyholders who had yet to make any claims were faced with large premium increases. In addition to causing an enormous amount of litigation, the issue became political and spawned much of the citizen protection and other legislative efforts we know today.

As a result, today's LTC policies are more comprehensive and adequately priced. They are also backed by state and federal requirements that mandate specific benefits, and provisions that protect policy owners against large premium increases.

The Cost of Long-Term Care

Long-term care includes a broad range of medical, personal, and social support services that people need when they become disabled or as they age. The majority of these services are custodial: personal care services or assistance with activities of daily living that family members and friends are able to provide at no charge. However, as care and support needs increase, paid care is often necessary to supplement family support, to provide respite to caregivers, and often to render a level of care available only in a formal facility.

The High Cost of Care

The medical, personal, and social services required in the event of an accident, a chronic illness, a disability, or merely because of the aging experience are the most expensive of all health care expenses. Considering the great numbers of people affected by these events, it is easy to understand why long-term care costs are so high and continually on the rise.

The actual cost of long-term care depends on where the care is delivered, the level of care provided, how long the care is necessary, and the area of the country where care is provided. Some people require a minimal amount of assistance with only one or two ADLs or only for a short period. Others require skilled medical care over a long period. No one can foresee who will need long-term care, the type of care needed, or how long the care will be necessary.

Homemaker and home health services are typically provided in two- to four-hour blocks of time, referred to as "visits," and are generally more expensive in the evening and on weekends and holidays. The costs of services in some community programs, such as adult day service programs, are often calculated at a daily rate but vary based on programming costs and whether the services are privately funded or supported by government subsidies. Many care facilities charge extra for services provided beyond the basic room and board charge, although some may have all-inclusive

fees.

While the evolution of the nursing home and long-term care industries has experienced many improvements, it remains far from flawless. As a nation and as individuals, we are increasingly devoting higher levels of spending to health care. Health-care spending that is specific to long-term care is no exception to the trend of rising costs.

Long-Term Care Costs by Level of Care and Facility Type
The following are indicative of costs associated with various levels and types of long-term care services as of 2009. These are national average median rates; actual costs vary dramatically by state and by geographic location within each state.

Homemaker Services
Non-certified but licensed provider rate—Nationally, the average hourly rate charged by a non-Medicare-certified but licensed agency for homemaker services is $17.48.

Home Health Aide Services
Non-certified but licensed provider rate—Nationally, the average hourly rate charged by a non-Medicare-certified but licensed agency for home health aide services is $18.50.

Certified and licensed provider rate—Nationally, the average hourly rate charged by a Medicare-certified and licensed agency for home health aide services is $46.22.

Adult Day Health Care
The national average daily rate charged by adult day health care providers is $53.59.

Assisted Living Facility
Nationally, the average monthly rate for a private one-bedroom unit in an assisted living facility is $2,825 (implying an average annual cost of $33,900). These rates exclude one-time community or entrance fees, which are charged by approximately one-third of all assisted living facilities. These nonrefundable fees average $2,400.

Nursing Homes
Nationally, the average daily rate for a semi-private room in a nursing home is $183.25 (implying an annual rate of $66,886).

Nationally, the average daily rate for a private room in a nursing home is $203.31 (implying an annual rate of $74,208).

Currently, the average stay in a nursing home is about two and one-half years. At today's cost, that would amount to a total of about $167,200 to $185,520, depending on whether the accommodation is a semi-private or private room. In only ten years, assuming an annual increase in costs of 5 percent, a two and one-half year stay in a nursing home will cost between $272,000 and $302,000.

A Comparison of Long-Term Care Costs by Facility Type

The following chart compares the types of services and range of costs associated with the more common long-term care providers and facilities.

The Cost of Unpaid Care

While it may not be as apparent as the hard dollars spent on LTC services, there is also a significant cost associated with unpaid care provided by friends and family members who are the backbone of long-term care. Family and friends provide essential assistance with ADLs and IADLs to loved ones of all ages every day. The contributions of informal, unpaid caregivers are not only the foundation of the nation's LTC system but also an important component of the U.S. economy, with an estimated economic value of billions of dollars. In 2007, about 52 million people provided LTC services at some time during the year. The economic value of family care giving was at least three times as high nationwide as that provided by Medicaid home- and community-based services spending on similar services.

It is also important to understand that there is a significant cost of care giving to the caregivers themselves. The toll is more than a simple accounting for hours. Costs include direct out-of-pocket expenses, lost work time, lessened productivity, and fewer hours that can be devoted to other personal pursuits. There is also a very great emotional and psychological cost associated with care giving. All of these costs increase in intensity with the level of care provided.

Planning for Long-Term Care

While a frank and informed discussion about present and future medical and personal needs can secure the most suitable type of long-term care at the right time, many people find the topic discomforting. Others are in outright denial about the possibility of requiring long-term care. While the aging population, longer life spans, rising health care costs, and an ever-increasing strain on government services ought to compel all those over the age of 40 to prepare for the possibility of long-term care, that's not the case today. Most Americans have not seriously considered or planned for the emotional and financial consequences of aging. Many are not even familiar with the care options available and most, when the time comes, will be shocked by the associated costs.

Some people fail to plan simply because of misinformation or lack of information. Many believe that Medicare, Medicaid, or their health insurance will pay for long-term care. Medicare pays for LTC services only for short period, and only if the care is required following hospitalization. State Medicaid programs pay only for the financially needy and only when other qualifying criteria are met. Traditional health and medical expense insurance does not cover long-term care at all. Citizens need to be aware of these facts and be informed of the options they do have with respect to long-term care. Having reliable information helps ensure that appropriate options are considered if and when the need arises. An informed citizen is more likely to retain choice and control over where and how services are provided.

Fear of aging and its associated problems are clearly obstacles to planning for long-term care. Unfortunately, fear often leads to denial, and denial prevents people from aptly assessing their long-term care needs and taking the appropriate action to address those needs. The advantages of planning ahead are many:

-Planning ahead for long-term care is important; because there is a good chance an individual will need some level of long-term care if he or she lives beyond the age of 65.

-Planning ahead helps one understand the available LTC services, eligibility criteria, cost, and public and private payment options.

-Planning ahead allows assets and income to be preserved for uses other than long-term care, including preserving the quality of life for a spouse or other loved ones.

-Planning ahead means less emotional and financial stress on family members.

-Planning ahead helps ensure greater independence if and when the need occurs.

Summary

Long-term care takes into account a variety of services, including medical and nonmedical care for people who have chronic illnesses, disabilities, or cognitive impairments that keep them from living an independent life. Long-term care helps meet both health and personal needs. The need for long-term care can surface at any age. The medical, personal, and social services required in the event of an accident, a chronic illness, a disability, or merely because of the aging process are the most expensive of all health care expenses. Having reliable information on LTC services, options, and costs can help ensure the availability of care at the time it is needed.