

# C H A P T E R 1

## **Eldercare Options Considerations in Choosing the Right Long-Term Care**

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### **Introduction**

A nursing home is not the only game in town. This chapter discusses nursing homes along with two other long-term care options—staying at home (in some cases, a family member’s home) and living in an assisted living facility.

It is impossible to say that one long-term care alternative is always better than another. This section discusses the options so that elders and their families can determine which is best in their particular circumstances.

**Who decides when care is needed and what care to provide?**

Preferably, the elder makes the decisions herself, with advice and assistance from family members and appropriate professionals. Decisions regarding long-term care can be anxiety provoking, and it will generally be important for the elder and the family to have the elder make or agree with the ultimate decision. Like anyone else, an elder will be more accepting of a decision made by her than one made for her.

Ideally, the elder and family will have discussed possible options well in advance of the time that long-term care is needed. If the possible need for long-term care is discussed early and often, elders and families are more likely to perform effectively when a potential problem arises.

An elder's decline raises difficult emotional issues. On the elder's part, she may find it difficult to admit need and to accept a loss of power and independence. Her family may also have difficulty accepting the elder's decline and, in addition, will likely struggle with feelings of guilt over the inability to meet all the elder's needs.

Also, a family may not be in agreement over what is to be done. It is not uncommon for family members (often adult children) to be at odds over the arrangements made for an elder's care.

For most elders, staying at home is a priority. Moving out of one's home can be a dreaded occurrence—both an admission of decreasing capacity and a loss of familiar and comforting routines.

To the extent possible, an elder should plan ahead and discuss with family members the point at which a move may have to happen. Consider what objective factors would indicate that a move should take place. Planning ahead will reduce the stress of decision making if and when the elder must consider moving. Communication among family members will help everyone involved feel confident that the best decision was made and followed.

A common reality, however, is that planning has not been done ahead of time. Furthermore, in many cases, the elder and the fam-

ily do not even agree on the need for long-term care. Most commonly, the family is concerned about the elder's increasing frailty and forgetfulness while she insists that she's perfectly capable of taking care of herself.

This guide does not presume to instruct families on exactly how to resolve such differences of opinion—every family has its own personality and its own dynamics. In some families, confrontation is an everyday fact of life. Other families are less accustomed to conflict, particularly those involving difficult topics such as a parent's mental or physical decline.

This guide encourages families to tackle the tough topics head-on. If an elder is acting erratically or if the family is concerned about the elder's safety or the safety of others, the family should try to talk with the elder about those concerns. Avoiding the problem is ultimately no solution and will only lead to more problems in the future.

### **What happens if the elder is not capable of making decisions?**

If an elder no longer has capacity to make medical decisions, the elder's family may need to ascertain whether advance planning has been done. See chapter 7 for more information on health care decision making.

## **Remaining at Home**

### **What services can help an elder stay in his own home or a family member's home?**

Various services available in many areas may enable an elder to stay in his own home or in the home of a family member, despite the elder's need for some assistance and health care. For example, in-home health care can be provided by a home health agency, through visits by a nurse or a home health aide. A personal care aide can provide assistance with dressing, cooking, chores, and other similar tasks.

During the day, the elder may be able to attend an adult day care center for meals, socializing, and services. Some adult day care centers are also qualified to provide limited health care. Adult day care centers may be particularly helpful for elders living with family members, if the family members work out of the home during the day.

Home-delivered meals are commonly provided through local senior centers and various charitable organizations. In many cases, these same organizations may be able to assist in modifying an elder's house to make it more accessible—for example, by adding grab bars in the bathroom or installing a ramp to the front door.

Actually, most at-home services are provided by family members and friends, whether the elder is living in his own home or in a family member's home. Of course, the feasibility of family assistance depends on whether the family lives in the same area and on the family members' other obligations at home and work.

The Medicare program may pay for home health care for Medicare beneficiaries who are considered “homebound”—that is, their mobility is so limited that they cannot be expected to leave the house for routine medical treatment. If the elder is terminally ill, the Medicare program can pay for hospice services, which are discussed on pages 120–21.

In many but not all states, the Medicaid program will pay for a package of in-home services for elders who are sick enough to otherwise be admitted to a nursing home. The idea behind the in-home care is that the elder benefits because he is able to stay at home, and the Medicaid program benefits because in-home care is less expensive than the nursing home care that would otherwise be required. Unfortunately, the availability of such in-home services is limited. State Medicaid programs generally have a cap on the number of Medicaid beneficiaries who can receive these

in-home services during a given year, and many states have a waiting list.

### **What factors should a family consider in planning to care for an elder at home?**

As always in these matters, advance planning is strongly recommended. Here are some issues to consider:

- With whom might the elder live, or how will she cope in her own home?
- If and how will the family share caregiving duties?
- How and for which services will family caregivers be reimbursed?

#### **WORD TO THE WISE . . .**

*Be realistic.* Family members may be motivated to do “whatever it takes” to keep the elder at home. Even with the best intentions, however, family members can only work so hard for so long.

Recognize that long-term care is more a marathon than a sprint. Plan ahead so that the primary caregiver is not driven to exhaustion. Ideally, family members and friends will share the workload. For example, one adult child could be the primary caregiver, and another could help with finances and medications. Out-of-town relatives might help with tasks that are manageable from afar and use vacation time to give the primary caregiver a respite.

Family stress and burnout can be reduced with planning. Regular check-in meetings among family members can also be valuable.

- What circumstances might indicate that at-home care is not workable—for example, caregiver burnout or a family's inability to move the elder from bed to wheelchair?
- How will a family caregiver get time off?
- Where will the elder move if the arrangement doesn't work out or needs to end for any reason?

## Assisted Living

### What is assisted living?

In general, an assisted living facility provides residents with room and board, assistance with activities of daily living (eating, dressing, toileting, bathing, etc.), and some level of assistance with health care needs. Assisted living is governed by state law, so the details of assisted living vary from state to state. In most states, an assisted living unit might be either a private unit or a shared room.

Most states use the term *assisted living*, although some states use other names to refer to this level of care. A state, for example, may use the term *personal care home* or *housing with services establishment*.

In the past, assisted living residents needed only minimal assistance with their activities of daily living, but this is changing. Increasingly, assisted living facilities are able to admit and retain residents who need daily health care or substantial assistance with activities of daily living. For example, some assisted living facilities can care for residents who are incontinent, have severe dementia, or are terminally ill.

Some assisted living facilities are small, with ten or fewer residents. In recent years, however, assisted living facilities are more likely to be larger institutions with one hundred or more residents.

Some assisted living facilities are affiliated with or adjacent to nursing homes (see following sections for more information on

nursing homes and continuing care retirement communities). An elder may wish to consider the advantages of living in close proximity to a spouse who may need nursing home care.

To this point, most assisted living care is paid through residents' income and savings. In most but not all cases, Medicaid reimbursement is not available for assisted living care. In some cases, a state's Medicaid program will pay for assisted living services for those residents who are sick enough to otherwise be admitted to a nursing home. As explained in this chapter's discussion on in-home services, this type of Medicaid program is often subject to enrollment caps and waiting lists.

Further information about assisted living is available from the Assisted Living Consumer Alliance, at [www.assistedlivingconsumers.org](http://www.assistedlivingconsumers.org).

### **WORD TO THE WISE . . .**

*Consider the pros and cons of assisted living.* It is both good and bad that assisted living facilities are now able to admit and retain residents with significant care needs. The good side is that elders have more options and that assisted living facilities may be more homelike than nursing homes. The potential bad side of assisted living is that, because assisted living facilities are much less regulated than nursing homes, the quality of assisted living can vary greatly. More often than not, an assisted living facility has neither a nurse nor a nurse aide on staff. An elder needing health care or significant assistance with activities of daily living should make sure that the assisted living facility is staffed and equipped to meet the elder's needs or that health care needs can be met by visiting nurse agencies.

**What is a continuing care retirement community?**

A continuing care retirement community offers all levels of care, from independent living to assisted living to nursing home care. Care is often provided in a campuslike setting with many buildings or houses, although some facilities consist of a single building. Continuing care is typically the most expensive option in long-term care. Oftentimes, a continuing care retirement community is affiliated with a religious denomination or other nonprofit group.

The benefit of continuing care is that an elder can move into a community and build ties while still independent and then move into appropriate levels of care as his needs for care and services change. For an elder who can afford it and is certain that a particular community is right for him, moving into a continuing care retirement community can be a long-term solution to many of the practical problems that can accompany aging.

Many continuing care retirement communities have long waiting lists, so an elder interested in continuing care should start shopping around sooner rather than later. Financial arrangements differ greatly from community to community. In a traditional model, an incoming resident pays virtually all his savings and income to the community in return for the community's promise

**WORD TO THE WISE . . .**

*Carefully read any continuing care contract.* Although continuing care retirement communities generally give the impression that an incoming resident is securing a home for the rest of his life, the contracts often give the community a great deal of discretion to terminate the contract and force the resident to move.

to care for him for life. Some communities require payment on a month-to-month basis, while other communities use a combination of these two models—the incoming resident pays a substantial initial payment, perhaps \$100,000 or more, and also pays for care on a month-to-month basis.

## Nursing Homes

### What is a nursing home?

In addition to providing room and board, a nursing home offers assistance with activities of daily living, skilled nursing care, rehabilitation, medical services, protective supervision, and therapy. Other names for a nursing home include *nursing facility*, *nursing center*, *convalescent home*, *convalesarium*, *long-term care facility*, or *sanitarium*.

Nursing homes serve people with great needs for assistance and care. Residents often cannot walk, and many need assistance with dressing, bathing, eating, and other activities of daily living. About half of nursing home residents have some form of dementia.

The staff of a nursing home includes registered nurses, licensed nurses, and nurse aides. Nursing homes must also have easy access to doctors and provide access to various health care services, including those of dentists and podiatrists.

Some nursing homes specifically provide care for residents with psychiatric disorders. Other nursing homes may offer specialized areas within the nursing home, such as an Alzheimer's disease unit. It should be noted, however, that all units of all nursing homes must be capable of providing care to residents with a psychiatric diagnosis or with Alzheimer's disease or another dementia. A nursing home's claim of specialization does not necessarily mean that the nursing home's care is any better than the care provided by any other nursing home.

Approximately 96 percent of nursing homes are certified to accept reimbursement from the Medicare or Medicaid programs. By accepting Medicare or Medicaid reimbursement, these nursing homes are obligated to follow the requirements set by the federal Nursing Home Reform Law. As discussed throughout this guide, the Nursing Home Reform Law establishes important protections for residents.