

# Is assisted living the right choice?

## THE PROMISE AND THE PITFALLS OF A RESIDENTIAL OPTION DESIGNED TO FILL THE GAP BETWEEN INDEPENDENT LIVING AND NURSING-HOME CARE.

Perhaps you've been worrying about Mom lately. Her arthritis keeps her from taking care of the house, and she has so much trouble reading fine print that you wonder how she can keep track of her medications. Some days she doesn't feel like eating, and even a daily phone call leaves you more concerned than reassured. Mom says she'll never set foot in a nursing home, but every day you drive past an assisted-living facility, and its tidy buildings and manicured grounds look like an appealing alternative.



**Assisted-living resident Helen Roberts (left), age 88, was interviewed in her Northern Virginia apartment by Trudy Lieberman for the Consumer Reports book on eldercare.**

Photos by John Harrington

Assisted-living facilities offer a relatively new way to care for seniors who can't manage on their own. A cross between an apartment building with services and a nursing home, these facilities offer residential units, which sometimes include a kitchen, housekeeping services, meals, transportation to doctors and activities, and various levels of personal assistance--all for a monthly rental fee. The brochures for assisted-living facilities highlight independence, support, and communal activities for the frail and disabled elderly.



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With the number of people who will need help with activities of daily living projected to increase by 51 percent in the next 20 years, assisted living is in a growth mode. The number of licensed facilities--built by independent chains like Sunrise, hotel chains like Marriott and Hyatt, and individual entrepreneurs--has increased 30 percent since 1998. Some communities now have many facilities to choose from, although rural areas may have few or none.

Today more than 500,000 people live in places loosely called assisted-living facilities, where the average age is 84. Most residents require help with at least three activities of daily living, such as eating, bathing, toileting, dressing, and walking. One industry survey found that nearly half of residents suffered from mild dementia or early to midstage Alzheimer's disease. Nearly one-quarter of facilities have special Alzheimer's units.

Assisted-living facilities are not substitutes for a nursing home. Many do not admit or keep residents who need ventilators or catheters, or help with continence problems. About 36 percent of all residents eventually go to a nursing home because the assisted-living facility cannot accommodate their increasing needs, and 2 percent go to nursing homes because they have exhausted the means to pay for care.

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The price of care at an assisted-living facility can exceed \$4,000 a month, depending on the size of the unit and amount of personal care needed. The financial arrangements are usually different from those of continuing-care retirement communities (CCRCs), which may require an entrance fee ranging in the hundreds of thousands of dollars. CCRCs offer a continuum of residential arrangements from independent living units to assisted-living and nursing facilities (see [Other options](#)).

## Promise vs. reality

Assisted-living entrepreneurs emphasize that their facilities don't look, feel, or smell like nursing homes. Yet some practically offer nursing-home care, with little government oversight, while others provide so little care that families must hire home attendants to meet their relative's needs.

"Appearance is 75 percent of the battle to get families to sign up," explained Patti-Ann Hopkins, a manager at a Marriott facility in Boynton Beach, Fla. "What sells the family are safety and security, value for price, the food, and a homelike environment."

And so facilities appeal to the aesthetics of residents and their adult children. Some facilities sport features like old-fashioned ice-cream parlors and 1940s-style jukeboxes. At one Sunrise facility the dining room is called the "servery" and the Alzheimer's wing "a reminiscence neighborhood."

Virginia Fraser, a long-term-care ombudsman in Colorado, warns that "the critical consideration is the philosophy of the place and how the staff carries it out." A fancy front room with Georgian-style furniture does not guarantee that a resident needing help with a bath every day will get it, or that the facility will accommodate a resident's declining eyesight with appropriate help and activities.

"Marketing assisted living is less about need than where adult children want their friends to know Mom is living," says Dr. Donna Yee, executive director of the Asian Community Center of Sacramento Valley, Calif., and a former associate research professor at Brandeis University.

While Yee was at Brandeis, she and her colleagues conducted the first national study of 396 residents in assisted-living facilities in the mid-1990s and found that although many experienced fairly independent and autonomous lives, they also had unmet health and long-term-care needs. Sometimes they were socially isolated, experiencing limited participation in activities or community life. Yee and her colleagues also discovered that those facilities that offered residents more autonomy had more avoidable negative health outcomes than facilities that offered less choice.

Therein lies the crux of assisted living: autonomy vs. supervision. Long before they sign on the dotted lines, adult children and their parents must understand those trade-offs and what they mean for quality of life.

Assisted living offered by many entrepreneurs embraces the concept of the "dignity of risk." This means that residents can make their own decisions about their care and safety, and even choose certain courses of action that others consider risky. For example, if a diabetic wants to eat cake and ice cream once a month, should that be his or her choice, or should the facility step in and say no? Should the facility allow a resident to use a walker even if she falls and hurts herself, or should the facility insist the woman stay in a wheelchair? Some facilities require prospective residents to sign contracts that include provisions for negotiated risk--that is, how much risk the resident is willing to assume and how much risk the facility will take.

Balancing a resident's desire for autonomy with his or her need for assistance and protective care is no easy task. "The reality is no one knows how to have people 'age in place' in assisted living with a good balance of choice and safety issues," says Dr. Joanne Lynn, director of the Center to Improve Care of the Dying at Rand Health, a research institute in Arlington, Va.

Autonomy vs. risk is one issue you'll need to consider when helping an elderly relative get

the care he or she needs. Consider, too, whether or not your relative can afford to stay in the facility for as long as it's appropriate.

If assisted living seems a viable solution (see [Other options](#) for alternatives), some careful comparison shopping is in order. What follows is a guide to the questions to ask--and the things to observe--as you visit facilities in the area where your relative wants to live.

## SHOPPING FOR A FACILITY

Be prepared to do some careful shopping to find a good facility. Start with initial visits to several in the area. Most residents we spoke with said that the quality of care and staff, and having someone to talk to, were more important than fancy surroundings. It may take several visits to evaluate those intangibles.

### First visit: The tour

On the first visit, most likely the director of marketing (who may, in effect, be doubling as a real-estate agent) will show you around. You will see the common areas--the parlors, library, dining room, laundry facilities, and patio. Then she (many are women) will show the available apartments. Where the apartment is located is very important. In many assisted-living facilities, units closest to the dining room or elevator are more desirable and therefore may cost more.

What your guide says or does not say offers clues to the quality of the facility. For example, if she doesn't ask any questions about your relative's needs, it may be a sign the facility is more interested in filling space than in the care your relative requires.

Observe how staff members relate to the residents. Do they talk with them and know them by name, or do they ignore them? Do they seem genuinely interested in the residents and what they are doing, or do they seem phony, putting on a show for prospective families? After you visit three or four facilities, you'll be able to tell.

**Look for signs of life or energy.** In most places we visited, residents seemed to prefer to stay behind closed doors, and there were few activities going on despite the full activities calendars posted on the walls.

If you see few residents in the common areas or participating in activities, it may signal that the facility is not full. A half-empty facility could bode ill for the facility's long-term finances. If a facility needs residents to fill up its units, you might encounter the hard sell. High-pressure tactics are always a sign to continue shopping.

When you do see an activity, note whether residents are really engaged and enjoying what they are doing. At a facility in Boston's Back Bay, residents gathered in the parlor on a late winter afternoon to hear a travel program. They asked questions, talked, and appeared to be truly interested in the presentation.

Observing activities is also important if you are placing a relative in the Alzheimer's unit. Margaret O'Kane, president of the National Committee for Quality Assurance, an organization that accredits HMOs, told how her mother gets no stimulation in an Alzheimer's wing at a Maryland facility. "She's in bed most of the time," O'Kane said. "The facility says it is going to change the situation, but nothing changes."

**Be specific about care needs.** Find out how the facility will accommodate your relative's current needs and what it will do as those needs intensify and increase. Be forthright and explain exactly what your relative's functional, physical, and mental deficits are and how they are likely to change. For example, someone with glaucoma or macular degeneration may experience a progressive decline in sight. How will the facility accommodate the decline?

When that question was posed to an admissions official at a government-subsidized housing unit in Boston, she referred us to the facility's Optelec system, a device that magnified print so residents with failing eyesight could continue to read their mail and other

printed matter. When the admissions director at a competing and somewhat glitzier facility was asked the same question, she told about how wonderful one blind resident was, a patronizing remark that avoided the question. If the answers you get don't make sense, or appear to brush off the problem, look elsewhere.

**What's in the contract?** Ask for a copy of both the rules and the contract. This is a test of the facility's interest in full disclosure. If there's reluctance to part with such crucial information at this early stage, consider it a red flag.

**Level of care.** Many assisted-living facilities have complex formulas for determining how much care your relative requires. Brighton Gardens in Austin, Texas, figures out how much time it will take nursing assistants to help residents perform various tasks, and then multiplies that by the number of times a resident needs services. The marketing official said that the facility places new residents in a higher level of care and then reassesses them after 30 days, possibly moving them to a lower level.

"We decrease the level of care for 50 percent of my residents," says Hopkins, of the Marriott facility in Florida.

It's important to know when periodic reassessments take place, since the level of care is linked to the amount you will pay. If you suspect the facility is trying to jack up its fees, you can secure an independent assessment from a geriatric-care manager.

## Additional visits: Fact-finding

It is very important for you or your relative to visit the facility two or three times. These visits should be regarded as serious fact-finding missions. Visit at different times of the day to observe the routines. If possible, join residents for a meal to get an idea of how tasty the food is.

Chatting with residents in the lobby or outside is the best way to gather intelligence. The facility may tell you that there is sufficient staff; residents may tell a different story--long waits for help, long waits for dining services, few people to talk to. The second visit is the time to inquire about a residents' council and find out how active it is. One resident noted that without the residents' council, the facility "would walk all over us."

**Does the staff seem interested in residents, or are they putting on a show for visitors? After you visit a few facilities, you'll be able to tell.**

The second visit is also the time to take a harder look at the physical surroundings. How accessible is the dining room? Can someone with arthritic hands hold on to hand bars easily? One Savannah facility was equipped with handrails that were nothing more than grooves in the wall that would be hard for someone to grasp. A competing facility in the area had handrails that protruded from the wall and were much easier for residents to hold on to.

Are there dizzying patterns on carpets or walls? These can make it hard for elders with poor eyesight to navigate. Observe the cupboard height in the kitchens. One resident our reporter visited had all her kitchen paraphernalia stacked on counters because she couldn't reach the cupboards.

**Staff training.** Ask about training in such areas as direct care to patients, safety and emergency care, first aid, CPR, sanitation, mental health and emotional needs, residents' rights, and medication administration. Get specifics: How many hours in what fields? Do they have continuing-education requirements? If your relative will be in the Alzheimer's or dementia wing of the facility, learn how the staff is trained to interact with difficult residents.

**Philosophy of negotiated risk.** Does this facility want families and the resident to engage in a process of care planning around issues of risk and autonomy? Negotiated agreements reflect a philosophy of consumer choice, autonomy, and independence, but they may also provide a way for the facility to escape liability if the resident suffers harm as a result of certain actions. If you go down the path of negotiated risk, have a lawyer examine your agreement.

**The care plan.** Ask who draws up the care plan, and how much input the resident and

family will have. All should have a say. If your relative is able to make decisions, the facility should ask about his or her preferences. A care plan drawn up solely by the staff is likely to be a source of trouble later when things go wrong.

## WEIGHING THE PAPERWORK

As you're touring various facilities, begin to ask questions about admission procedures and contracts.

**The application.** When you review the application form, don't be surprised if it asks for detailed financial information about your relative's savings and income. The facility wants to make sure you or your relative can pay the basic price for the unit, the monthly fees, plus the inevitable annual rate increases. But just as important, the application tries to find out whether your relative "qualifies" for care in the facility. At Hale House in Boston, residents must be able to get themselves up and dressed and down to the dining room without assistance. If they can't, the facility doesn't want them.

**Is there a waiting list?** Facilities vary in how their waiting lists work. At some, anyone who does not accept an offer when an apartment becomes available moves to the bottom of the list. At others, the facility simply calls the next person on the list, leaving the others in the same position.

To keep your relative on a waiting list, you will most likely have to leave a deposit, usually ranging from \$300 to \$500. Ask if the money is refundable if your relative eventually decides not to move in. And if he or she wants to go through the application process, will the facility allow the deposit to be used as an application fee?

**Where will your relative live?** Contracts should specify a unit and provide for flexibility when it comes to bringing personal furnishings, who can come to live or visit, and whether the same unit will be available after a temporary hospital stay. Many contracts are silent on those points. Be sure you are clear about what happens if a resident needs hospitalization. Will payment still be due? What will happen after discharge? Nursing homes are required to hold a room for Medicaid patients. But many assisted-living facilities are not. Be sure that yours will. Going to a new facility can be disorienting to an elder who has just experienced an acute illness.

**Are meals included?** Contracts usually specify which meals are provided. Will the facility provide a special diet if needed? Does the facility give credits for meals not eaten or provide tray service if a resident is ill and confined to the apartment? Is there an extra charge for this? These extra charges can add up.

**How do residents get about?** Contracts should specify who will provide transportation and to where. Some contracts don't say, or they specify that residents must arrange their own transportation. When they do mention the subject, contracts may impose restrictions and conditions.

**Can residents see their own doctor?** Most residents prefer to see their own doctor, but in some facilities, they may have to use the doctor the facility provides. If a facility requires all residents to use the same doctor, and if that resident also belongs to an HMO that requires the use of its own physicians and other providers, he or she could be caught in the middle, unable to obtain medical care without incurring unnecessary out-of-pocket expenses.

**Who is in charge of medications?** Contracts should specify who is responsible for administering, coordinating, and scheduling medications.

**What if a resident's health fails?** Few contracts specify what happens when a resident's physical or mental status declines. Ideally, contracts should specify that the facility will devise an individual program to accommodate those needs. But instead the contract might say residents can hire their own aides and assistants to help. Many facilities are neither licensed nor equipped to deal with the increasing medical needs of their residents.

**Who decides about transfers?** It's not uncommon for residents to live in several units during their stay in assisted living--first in a private unit and then, as money runs low, in a shared room, perhaps in an undesirable wing or floor. Nor is it uncommon for residents to

be sent to a nursing home or placed in a higher level of care as their physical or mental capacity declines. Knowing who makes the decisions about transfers, the factors they're based on, and whether a resident has any say in the matter is crucial. Beware of contracts that say decisions are "determined" by the facility.

**What if it doesn't work out?** See whether the contract provides for a probationary period during which the resident decides if he or she is suited for assisted living. If no probationary period is allowed, will the facility offer a prorated refund of fees already paid if your relative decides to move out after a few weeks?

Even though the marketers promise that your relative can "age in place," state law or the facility's own policy may undermine that promise by limiting the services that can be provided. Contracts should allow for a minimum 30-day notice if the facility wants to end the agreement.

**Some 40 percent of assisted-living facilities charge extra for administering medications.**

**Who pays the costs?** Almost 95 percent of assisted-living residents pay for care out of their own funds. The rest get help from family and friends and occasionally from state agencies. Monthly fees for assisted living can easily exceed \$3,000 or \$4,000 a month for rent and care, and there is little public funding available to help. Generally, Medicare does not pay unless skilled-nursing care is needed and given in certified facilities. But Medicare does pay for some skilled care if your relative meets the requirements for the Medicare home health benefit. In these cases it may also pay for some personal-care services.

Thirty-seven states pay for care in assisted-living facilities through Medicaid. To be eligible for Medicaid, your relative must be poor or become poor by spending down assets in order to qualify. Because states limit the number of people served through waiver arrangements, you may encounter long waiting lists even if your relative qualifies financially. Your state department of social services or the Assisted Living Federation of America (703 691-8100) can tell you whether or not your state pays.

## Comparing costs

Be forewarned that residents of assisted-living facilities face a web of charges--everything from the monthly fee to specific charges for various services the staff gives to help them through the day, even walking them to the dining room. It's difficult to disentangle different fee arrangements. Although pricing can be complicated, assisted-living facilities generally use one of these ways to charge for their services:

- ▶ **Flat or bundled rate.** With this arrangement the facility estimates the average amount of care residents will need. Everyone pays the same for personal-care services that are folded into the basic rent for the living unit.
- ▶ **Tiered rate.** A facility may include four or five tiers, or rate levels, in its pricing structure. Each tier represents a different level of care needed by a resident.
- ▶ **Flat rate plus an hourly charge for assistance.** Hourly charges add up. At one Boston facility, residents could be charged an extra \$6 for every 15 minutes of personal care they needed beyond what was specified in the base rate. Fees can be as outrageous as charging for tying shoes or opening draperies.
- ▶ **Onetime entrance or community fees.** These can equal a month's rent, though they rarely exceed \$5,000. One facility that was charging \$2,000 called it a membership fee.

**Rate increases.** Caring for physically and mentally impaired elders is labor-intensive and very costly, and most facilities raise their rates 3 to 5 percent each year. Some residents run out of money while still in an assisted-living facility, especially if they stay a long time. Eighty-eight-year-old Helen Roberts, who lives in a Sunrise facility in northern Virginia, moved into the facility in 1990 and paid a monthly fee of \$2,432. One year, Sunrise announced an increase of 5 percent, but Roberts's cost-of-living raise from Social Security that year was only 2.4 percent. Residents, working through their active residents' council, prevailed on Sunrise to limit the increase to 4 percent. "None of this was written in the entrance papers," Roberts said. By 2000, she was paying \$3,525 a month just for the unit and meals, but no additional care.

**Additional costs.** Sometimes residents require visits from home health aides in addition to the assistance the facility staff provides. Some 40 percent of assisted-living facilities charge extra for administering medications. Ask if the facility requires residents to use certain home health agencies or pharmacies. One facility switched to a new pharmacy. The old pharmacy charged one family \$4.44 for 27 Brethine tablets; the new one charged \$102.93 for 30. Using the new pharmacy was the only option if the family wanted the facility to administer their mother's medications.

## RECOMMENDATIONS

- ▶ Decide if your relative really is a good candidate for assisted living. For people who dislike the idea of communal living, home care, sometimes in combination with adult day-care programs, might work better. But for gregarious people who are beginning to experience a decline in function, assisted living might be a good option, at least for a while.
- ▶ Take a realistic look at your relative's financial picture. Do some hypothetical financial projections; look ahead at least four years or maybe more to see if he or she can continue in an assisted-living facility. Consider the likely possibility of increasing frailty, needs, and expenses, as well as increases in monthly charges. Will future income and assets cover those contingencies?
- ▶ Carefully consider the philosophy of care given by the facility. Does the facility seem caring and concerned about your relative or are personnel more interested in keeping units filled?
- ▶ Be sure you understand what the facility can and cannot do to accommodate your relative's increasing frailty. Will personnel help you make arrangements for care that is needed but that the facility does not provide? Can you afford the additional cost?
- ▶ Look beyond a facility's fancy interior. Is the space functional for residents who may have different kinds of canes, walkers, wheelchairs, and abilities to navigate distances? Does the facility provide residents with camaraderie, activity, and support?

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