

WHO WILL CARE FOR YOU  
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With more of us living longer than ever before, understanding the facts about elder care and assisted living will help you and your family be prepared and protected. Here, how to look beyond the fancy lobbies and marketing hype to find a residence that will keep you or a loved one safe and happy, at a price you can afford. By Penelope Wang

In 2010 Wallace Kirkpatrick, 89, was living alone after his wife died. A friend suggested that “Kirk”, as everyone called him, get an apartment in the assisted living facility where he also lived. Kirk soon settled into Esplanade Gardens. “He had a buddy there, and he got along with the director, so he fit in very quickly,” says his daughter, Tara, who lives nearby. Kirk was especially pleased by the dining service, which made grilled bacon-and-cheese sandwiches, one of his favorites, on request.

For six years Kirkpatrick was happy. But by spring 2016, when he was 95, he began to show small signs of cognitive impairment. “Once he forgot where he was going, and another time he tried to unlock the apartment net door to his by mistake,” Tara says. A newly arrived facility director insisted that the incidents meant Kirkpatrick needed more supervision than the residence could provide. That meant his family would have to move him to a facility with a memory care unit or hire additional caregivers.

The family was reluctant to consider changing residences. “It was too early to move him,” says Tara, 61, a speech-and-language pathologist. “My dad was still very functional and would have been surrounded by people far more impaired.” The family met with the director and agreed to hire private caregivers to keep a closer eye on Kirkpatrick.

He had veterans disability benefits that covered the additional costs, which came on top of the \$4,000 per month for room, board, and an aide, who checked in several times a day and helped him shower and dress. With the additional aides, Kirkpatrick was permitted to remain in his apartment until he died in March 2017. “We couldn’t get it into our heads how we were paying for assisted living, when there was not much assistance,” Tara says.

Jack Collins, executive vice president of SilverCrest Properties, the parent company of Esplanade Gardens, declined to comment on the Kirkpatrick family’s experience.

#### THE CAREGIVING GAP

For older Americans, assisted living offers a compelling promise. Your aging parent can live in an apartment with hotel-like services and receive help with medication, bathing, and other tasks of daily living.

By contrast, a nursing home provides 24/7 care for seniors needing medical support. Other kinds of senior living communities are designed for people who are more active and high-functioning. But these differences are very loosely defined, which can make comparing facilities difficult. And whereas more hospital-like nursing homes are regulated at the state and federal level, oversight of assisted living facilities is uneven at best. A good one can be an excellent choice for someone who can no longer live on his or her own. A bad one could put your loved one at risk.

Assisted living is also a growth industry. As of 2014, about 835,000 older Americans resided in these facilities, up from 733,300 in 2010, according to the Centers for Disease Control and Prevention. But all too often, as the Kirkpatrick family discovered, assisted living communities lack the resources, or expertise to meet the needs of a population that requires increasingly intensive medical care.

Seniors in assisted living tend to be older and sicker than previous generations. In 2016 the average move-in age was 84, with a large number of seniors arriving after a medical emergency, according to A Place for Mom, a national senior housing referral agency based in Seattle. Studies show that more than half of residents have some form of cognitive impairment, according to Paula Carder, an associate professor at the Institute on Aging at Portland State University in Oregon. “Many assisted living facilities are taking residents who have no business being there,” says Amy O’Rourke, president of the board of directors of the Aging Life Care Association, an organization of aging-life-care experts, also known as geriatric-care managers.

Not surprisingly, consumer complaints about assisted living are on the rise, according to long-term-care ombudsmen, trained advocates who operate in all 50 states. Some 55,000 complaints were filed in 2015, compared with 50,126 in 2012, almost a 10% increase. In a recent survey of ombudsmen for Consumer Reports, the National Consumer Voice for Quality Long-Term Care, an advocacy organization, found that the most frequent complaints included understaffing, delays in response to calls for assistance, and threatened eviction. About 80% said their state government doesn’t provide sufficient regulatory oversight for assisted living facilities.

That’s not something you’re likely to hear from assisted living providers. “The marketing and sales people are trying to fill apartments,” O’Rourke says. “They’ll tell you they’ll take care of you for the rest of your life.” They’re also likely to tout their high-end amenities, such as wine cellars, libraries, and calendars crowded with cultural events.

The industry’s own surveys show high rates of satisfaction with assisted living, says Rachel Reeves, a spokeswoman for the National Center for Assisted Living, an organization that represents the country’s assisted living and other long-term-care communities. She says the NCAL “discourages undisclosed or exaggerated information” because doing so “diminishes trust and damages the relationship between the assisted living community and the consumer.”

Attractive amenities can contribute to a hefty price, mainly paid out of pocket. In 2016 the median cost for a one-bedroom was \$3,638 per month, or \$43,539 annually, according to a 2016 survey by Genworth, a long-term-care insurance provider. In some regions, costs can exceed \$60,000 per year (see attached map). Medicare generally does not cover long-term care. Most states provide for some Medicaid coverage of long-term care in assisted living, but the coverage varies widely by state, and to qualify, the resident must spend down his or her assets and meet other criteria. Not-for-profit continuing-care retirement communities typically provide funding for residents who start out in independent living, then move to assisted living and later run out of money. Otherwise, the resident would have to move out unless family members can tap other funding. Many nursing homes take Medicaid, but at press time, because of the ongoing healthcare debate in Congress, the program's future funding was uncertain. Identifying the right assisted living facility for yourself or your parent is difficult, and loose regulatory oversight is a main reason. Under federal law, nursing homes must provide adequate nursing staff and meet other standards. But assisted living is not governed by federal rules. Each state makes its own rules, which are often minimal – some don't require that a facility hire a licensed nurse, for example. Many advocacy groups, including Consumer Reports, argue that stronger regulations are needed for assisted living. (See attached page "Protections Consumers Need") "We are concerned that there isn't enough effective public oversight, including from the federal government," says Chuck Beil, programs director at Consumers Union, the policy and mobilization arm of Consumer Reports. The NCAL doesn't see it that way. "Assisted living is unique to each community it serves, whether in size, services, or specialty, which makes it inappropriate to regulate on a national basis," says the NCAL's Reeves. "State regulation is better suited to meeting the needs of local communities."

## A SHORTAGE OF STAFFERS

More regulation would probably improve residents' access to assistance, consumer advocates say. It's not uncommon for assisted living facilities to have only one or two direct-care staffers per 20 residents at night and perhaps one or two on duty per 15 residents during the day, says Carder at Portland State University. The staffers tend to be paid low salaries, often minimum wage. Nurses are also scarce—a handful of states have provisions regarding how many hours a nurse needs to be on call, or on site, so quite often facilities have no nurse present.

Staffing shortages recently sparked a lawsuit, filed on behalf of Louise McGraw and Charlotte Rogers, who have since died, although the case is still progressing. Both lived at Greystone In, a West Virginia facility owned by Chancellor Senior Management. The plaintiffs' attorneys, who are seeking class-action status for the lawsuit, allege that Chancellor bases its staffing on the parent company's labor budgets and profit goals, and not on an assessment of residents' individual care needs, as contractually promised.

The lawsuit alleges that McGraw fell, broke her hip, and was hospitalized because she did not get assistance she was entitled to by Greystone Inn. According to the lawsuit, McGraw repeatedly became dehydrated, she was left unattended, and her calls for help were ignored.

Rogers was hospitalized for dehydration with four days of admission to Greystone, the lawsuit alleges. After her discharge from the hospital, she returned to the facility. But she was hospitalized two more times for dehydration, malnutrition, and urinary tract infection.

Executives from Chancellor did not return calls for comment. Reeves says the NCAL strongly encourages facilities to provide care by “assessing the staffing needs for each unique resident.”

Adequate staffing is especially critical for dementia care, a fast-growing service now offered by about 60% of assisted living facilities. It typically costs about \$4700 per month. Although Carder says 38 states require dementia care training for the staff, she adds that only 16 states require a license or certification for dementia care units.

## MAKING THE RIGHT MOVES

Despite these challenges, families can find high-quality assisted living facilities. But start your search well before you or your parent actually needs care. If your parent’s health declines, assisted living might not even be an option, says Deborah Fins, an aging-life=care expert in Worcester, Mass. Many facilities will not take people who are wheelchair bound or need help with multiple chronic conditions, but some allow residents to stay if they become more infirm. To help you target your search, here are four key questions to ask:

1. What kind of help will the resident need? Perhaps your parent no longer drives and is becoming socially isolated. Or he or she can’t manage stairs or forgets to turn off the oven. For seniors who need moderate amounts of support, assisted living could be the smart choice. Assisted living is working well for Sharon Koenig, 76, who lived alone for two years after her husband died. “I kept waiting for him to come in the door” Koenig says. She also was having trouble tracking her medications. With help from an aging-life=care expert, who is familiar with local facilities, Koenig looked at several senior residences, including a small nursing home. Unlike some of the other places, Regal Palms in nearby Largo, Fla, a large facility with several levels of care, offered a varied menu of activities. Last October, Koenig moved to the assisted living section, into a two-bedroom apartment that has space for her 50-gallon aquarium. She gets help with medication but still does her own laundry. “Some people might be afraid of a big place, but I think it’s better,” she says. “There’s always someone to have dinner with.” *Smart Move:* Make sure your family member has a medical evaluation from a primary care doctor-or a specialist, if your parent has an illness, to understand the level of care required, as well as how those needs might change. For more perspective, hire an aging-life-care expert to help point you to appropriate residences. “Given the wide variation in the types of services provided by assisted living communities, it’s well worth spending the several hundred dollars for a professional care manager,” says Stephen Maag, a director at LeadingAge, an association of nonprofit senior-living groups.
2. How good is the quality of care? Make sure the residence is licensed to provide assisted living, to ensure that there’s at least a minum level of oversight. Take a close

look at the residence's inspection record, which indicates how often it has been checked or whether it has had complaints. See "10 Helpful Resources" on the attached page. Some states, such as Florida and California, maintain consumer friendly assisted living websites that list inspection records and regulatory actions. But some states do not, or they fail to update them. You can also ask your state ombudsman's office about a facility's complaint record. In the end, the best information about quality of care could come from people who visit facility residents, as well as from the residents themselves. Ask the residents specifics about the care – whether meds are delivered on time, for example, and how management responds to complaints, suggests Liz Barlowe, an aging-life-care expert in Seminole, Fla. Try to make multiple visits to the residence, including at meal time and on weekends. Most facilities will welcome you even if you don't have an appointment. Talk to the residents, and see whether the staffers seem happy or appear overworked. *Smart Move:* Ask how the residence would handle a fall, a common occurrence. Would a nurse be on hand to evaluate your parent, or would he be sent to the emergency room? And ask whether "the facility provides an on-site clinician or medical staff that can help the reside avoid the expense and health risk of an unnecessary trip to the ER or a hospitalization," says Alan Kronhaus, M.D., CEO of Doctors Making House Calls, a North Carolina medical group that provides on-site healthcare to assisted living residents.

3. **WHAT ARE THE REAL COSTS OF CARE?** Ask for a written list of the fs, and make sure the information is included in your contract. See "Putting the Contract under a Microscope" on the attached page. Some facilities have all in costs that cover room, board and care for particular level of assistance, and others have point systems or charge a-la-carte. See "11 Ways to Afford the Care You Need," on the attached page. Be sure to get clear information about the circumstances that could trigger higher or additional charges and how the facility assesses those fees, says Patty Ducayet, state long-term-care ombudsman for Texas. What would it cost to have your dad driven to a doctor 10 miles away versus 5 miles away? Is it okay to hire private aides? *Smart move:* Ask about the policy for lowering fees. Say your mom requires a higher level of care for a week to recover from a hospital stay. How quickly can the fees be cut when she has recovered? "Bumping down the charges tends to take longer than bumping up," says Karen Jones, a state long-term-care ombudsman I San Luis Obispo, CA.
4. **CAN YOUR PARENT BE KICKED OUT?** Involuntary discharges rank among the top complaints in most states, according to the National Consumer Voice survey. Discharges are usually triggered by lack of payment or care needs that exceed the facility's capacity to provide the services. The discharge terms should be detailed in the contract, as well as the required amount of notice you'll receive, which is typically 30 days. For Jill Goldberg, the possibility of her mon's discharge was unexpected. Her mon, Sylvia Wenig, 94, was living in Brookdale West Boynton Beach in Boynton Beach, FL. "We'd been getting great care there," says Goldberg, 61, who lives near Boston. But after a hospitalization, Wenig lost her mobility and was not allowed to return to the facility.

Goldberg asked if her mother could return for a week or two to allow time to find another facility, but Brookdale refused. Goldberg says she persuaded the hospital to let her mother stay a few more days, and with help from an aging-life-care expert, she moved Wenig to a nursing home. Says Brookdale spokesman James Hauge, "For residents who require more than the community is able to provide, we inform them of other care options and actively help them find a community that can meet their new care needs." *Smart Move:* Don't rely on the marketing director's assurances that your parent will be able to age in place. "Verbal agreements are nearly impossible to prove," says Jones, who recommends getting the promises in writing. With assisted living, it's better to know exactly where you stand.

**A GUIDE TO DIFFERENT COMMUNITY TYPES:** All assisted living facilities offer communal living, but their physical settings vary widely. Here are the main types.

**Apartment-Like Living:** Many residential care communities where residents rent an apartment with a small kitchen and private bath. They also offer communal dining and shared activity rooms, such as libraries and fitness facilities. About 68% of residents live in facilities with 50 or more people, according to the Centers for Disease Control and Prevention. The biggest places typically are part of for-profit chains, including the three largest, Atria, Brookdale, and Sunrise.

**Small Group Homes:** Sometimes called board and care, these assisted living residences offer a more intimate, homelike feel, housing just four to 25 people. These smaller places are often located in residential neighborhoods, where seniors can rent single rooms, share common spaces, and dine together.

**Continuing-Care Communities:** Though most assisted living facilities are standalone, some are connected to nursing homes or are part of continuing-care communities that offer multiple levels of care, from independent living to nursing-home care. Residents can move from one level to another which may mean a move to a different section if his or her healthcare needs change.

**Specialized Care:** Some assisted living facilities offer specialized services for particular medical conditions, such as Parkinson's disease, depression, and diabetes. But as the U.S. population ages, the biggest trend has been the number of assisted living facilities offering dementia care, says Sheryl Zimmerman, director of aging research at the University of North Carolina at Chapel Hill. Today about 60% of residential care communities provides a dementia care program. And almost one-quarter of assisted living communities maintain a dedicated floor or wing for memory care, or they are standalone facilities that serve only people who have severe forms of dementia according to the CDC.

**WHY MAKING FRIENDS AND FITTING IN ARE ESSENTIAL:** The right assisted living facility will help your parent feel comfortable and stay engaged, which can improve health and happiness. A particular assisted living facility might look like a solid choice based on location, care services,

and your family's finances. But what's also important is finding a good fit for yourself, or for Mom or Dad, a place where you or they can feel comfortable socially and make new friends. "A person's physical and psychological wellbeing can be improved by staying active and engaged," says Carolyn McClanahan, a financial planner and doctor in Jacksonville, FL. Here are tips for finding a good match.

**Use Your Instincts.** Look for activities and facilities – such as field trips, a book club, or a pool – that your parent(s) might enjoy with others who have similar interests. Consider the size of the residence, its appearance, and how you see staff members interacting with residents and each other. For a potential resident, "sometimes it is just kind of a gut instinct: Do I feel comfortable here?" says Stephen Maag, a director at LeadingAge, an association of not-for-profit senior-care groups.

**Visit Strategically.** To really get a feel for a place, talk to as many residents as possible and make multiple visits at different times. Arrange for Mom or Dad to observe or participate in one or two activities that are appealing. Consider an overnight visit, if offered.

**Ask about the Welcoming Strategy.** The initial weeks after a move could be emotionally difficult. Your parent will be adjusting to a smaller space, as well as unfamiliar faces. "These places can be very cliquish," McClanahan says. Still, the better facilities help residents feel at home as soon as possible, says David Schless, president to the American Seniors Housing Association, an Industry group. That might involve a plan to connect Mom with other retired teachers, or bring your Dad into the bridge group.

**Help, but Don't Hover.** Visit, but avoid weighing in on every small concern. "Let your parents do for themselves as much as they can do," says Jeff Pine, an aging-life-care expert, also known as a geriatric-care manager, in Santa Fe, N.M.

**Touch Base with the Staff.** Check in with a manager about how your parent is adjusting. Mom might be making friends and enjoying activities, despite complaints you may be hearing. You might also make specific requests, such as asking a staff member to remind your parent of an activity of particular interest.

## PUTTING THE CONTRACT UNDER A MICROSCOPE

Getting the fine print right from the start is your family's best protection. Most assisted living residences will ask you to sign an admission agreement, which is a contract, before moving in. Don't rush to sign. You'll want to look at the contract carefully and ask an elder-law attorney to review it. "You want to be aware of all the terms, since you may not have much recourse once you sign," says Lori Smetanka, executive director of National Consumer Voice for Quality Long-Term Care, an advocacy group.

The cost for a legal review will vary from a few hundred dollars to a couple thousand, depending in part on where you live and the particular facility, and whether a contract may be

negotiated. “If the lawyer already knows the language in a facility’s contract, it may take only an hour or so to go over the details,” says Hyman Darling, president of the National Academy of Elder Law Attorneys, a trade group. Here are four key provisions to consider.

**Cost of Service.** Be sure you understand the fees listed in the contract and how they are assessed. Some facilities might charge a comprehensive fee for room, board, and care, others might have a tier of charges that kick in for higher levels of care. You are also likely to be charged a move-in fee, says Deborah Fins, an aging-life-care expert in Worcester, Mass. Most contracts are for one year, so fees are likely to increase at each renewal.

**Responsible Party.** If you are signing the contract on behalf of a family member who will pay the bills, don’t let yourself become financially liable unintentionally. “Make sure you are identified as an agent, not the responsible party,” says Shirley Whitenack, an elder-law attorney in Florham Park, N.J. You should have power of attorney to act for your parent, and the term “attorney in fact” should appear after your signature.

**Terms of Discharge.** The contract should include the conditions that could lead to an eviction, called an involuntary discharge, as well as the required notice, typically 30 days. Often this wording is left vague. It might say, “We can no longer meet your needs,” for example. “If the language is not specific, the management can make decisions on an ad hoc basis,” says Eric Carlson, directing attorney for Justice in Aging, an advocacy group. Ask for the terms of discharge to be limited to specific reasons, such as nonpayment and care needs that the facility is not licensed to provide.

**Mandatory Arbitration.** Many residences include an arbitration provision in their contracts, requiring disagreements to be settled by a third party and not in court. The arbitration clause is sometimes voluntary, but often it’s required. Consumer Reports believes mandatory arbitration is not good for consumers and should be banned. If a forced arbitration clause is in your contract, cross it out before signing, or write in “refused”, says Martin Kardon, a Philadelphia trial attorney specializing in elder care. There’s little risk that your loved one won’t be admitted if you try this. If the management insists that arbitration is mandatory, you can decide whether it’s worthwhile to agree. You should also make sure you receive a complete copy of the signed contract, Kardon says. That way there will be no question about your rights.