

# When You or a Loved One Can No Longer Live Alone

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## Summary

Perhaps you or someone you care about is simply getting older and more infirm. Or perhaps there has been a change in medical condition. Or maybe someone else who was living in the same home or nearby and was helping out in important ways is no longer going to be available. Any of these are good reasons why a person or couple who was living independently might no longer feel comfortable doing so, or even be able to do so.

This paper describes some of the options that exist in this situation, and identifies the key factors that probably should influence the decision about what to do next. It also points you to outside resources, helping you find both general information and help in your own locality.

## Your main options

For one reason or another, some of these will probably not be good possibilities for you. But let's at least survey the landscape first:

1. ***Staying where you are, and enlisting outside help.*** You might find a friend or relative to live with you. You might advertise for a live-in companion who will help out in exchange for free rent, or some similar arrangement. You might find government, church, or charitable services to help with your needs. Or you might pay for professional services (medical and/or other), with or without insurance covering some of the cost.
2. ***Moving somewhere else*** that would be easier for you. Perhaps you could by all right in a place without stairs, or an apartment instead of a house, where outdoor maintenance and indoor repairs were someone else's responsibility.
3. ***Living with a child or some other relative or friend.*** You might even locate a stranger who would take you in as a boarder and help take care of things you were having trouble with, if you paid rent and/or contributed in other ways.
4. ***Signing up for an assisted living facility*** where you live as independently as you can for as long as you can, but services (whether medical or non-medical or both) are available. Note that continuing care retirement community (CCRCs) are generally not an option if you already are unable to live on your own, so these are not dealt with in this document.
5. ***Entering a nursing home,*** where you can get 24-hour supervision and/or intensive nursing care (or a hospice, if you are mortally ill).

**IMPORTANT: Don't wait until the last minute.** Start considering your options at least six months before you expect to make a change, if you can. This is an important decision and you are likely to have quite a few alternatives available to you. Whether many of them look good, or whether none of them look good, choosing can be complicated and emotionally difficult. It is best not to be making this kind of decision in a hurry, or when you are physically or emotionally ill.

In addition, most of these options can take months to implement ó desirable facilities often have waiting lists, and any kind of relocation is best done with careful thought and planning. If you have to make an emergency decision, you will have fewer choices, and you may not be in a good position to select well even among those.

### **How to decide which option is best**

Here are the main questions that should be asked by (or on the behalf of) the person(s) who need to make a change:

- What level of medical care will be needed, and what kind of help with daily living will be needed? Are there safety issues to take into account? (The Medicare website has a handy checklist of common activities and services and other issues you might want to use, at <http://www.medicare.gov/nursing/checklist.pdf>.)
- Are lifestyle issues important? Do you want to have certain activities still be part of your life? Is it important that you live with or near certain people, or near a certain place or organization (church, club, hometown, etc.)? Is a certain level of comfort or privacy or a certain amount of space needed to make life enjoyable?
- How important is personal independence? In what areas of your life can it be given up or compromised? In what areas would this be especially hard?
- What are the financial issues? What does each option cost you or others out of pocket? Which options are subsidized by outside parties, or offer tax advantages? In what ways might a change save you money?
- What is likely to happen next? What if you become sicker or more infirm? If you are part of a couple, what if your partner becomes infirm ó and would it affect your plans if you knew which of you would die first? What if you live a long time ó which options are sustainable and, for those that would work only temporarily, is there a plausible next step?

Keep these questions in mind as we look at the pros and cons of the various options.

We are assuming here that you are making this decision yourself or with others close to you. If the person who needs help is a parent or other person far away, you might want to find someone to help you in that locality. Even in your own area, you might want to get the advice of someone who has done this many times before. The National Association of Professional Geriatric Care Managers website can be used to help find a suitable adviser (<http://www.caremanager.org>), or you might ask doctors or physicians you know if they would recommend someone in particular. Bear in mind that professional care managers generally receive \$100-150/hr. (or maybe \$250 or so in high-cost urban areas), though sometimes they will help find a facility for free, because the facilities pay the fees. Other resources for caring for elders at a distance can be found at <http://www.cfad.org>.

If you have a social worker or care manager you trust, consult with that person, too. The Federal Administration on Aging ( <http://www.aoa.gov>) will help you locate the nearest **local Area Agency on Aging**. These offices have been set up specifically to help people in your situation. This should be one of your principal resources.

The U.S. Dept. of Health and Human Services also sponsors the Eldercare Locator Service. By calling 800-677-1116 toll-free, or by answering a few simple questions at <http://www.eldercare.gov/Eldercare.NET/Public/Index.aspx>, you can find out which state and local agencies help with elderly services in your area.

And of course, consult with your family members. This is an important decision for everyone, and everyone might have something to contribute, even if only a personal impression or concern.

### **Option 1: Staying where you are, but getting more help**

#### ***Advantages:***

- If the care you need can be brought to your door, you get the comfort and convenience of home living. You get to stay in your same neighborhood and can retain most if not all of the same network of friends and activities you've had for years.
- Doctors often recommend care at home, if it is feasible. It tends to boost morale, and that is good for both body and soul. Living at home supports your sense of independence, control, and emotional and physical security at a time when you might feel these slipping a bit, while also maximizing your privacy. Even hospice care is now provided at home more often than in professional facilities.
- If your care needs are light or moderate and able to be provided at home, this is usually cheaper than getting the same care at a residential facility ó assuming you are paying out of pocket. You pay for only what you need.
- If you are elderly, you may be eligible for rent rebates, real estate tax rebates, and protection against eviction, excessive rent increases, or condo conversions.
- Care costs exceeding 10% of your Adjusted Gross Income may be tax-deductible. You generally can deduct the cost of in-home medical care, as well as help with personal care, such as feeding or bathing (but not for housekeeping and home maintenance). The cost of medically necessary home improvements is also deductible, as is the cost for adult day care, including transportation. Consult your tax advisor.

#### ***Things to watch out for:***

- You could be caught by surprise, especially if you live alone. A sudden medical problem or accident could happen when no one was there to help (though telephone and beeper services can help reduce these risks at fairly reasonable costs).
- Unlike at an assisted living or nursing facility, you or your family will have to take the initiative to identify, locate, monitor, and fund whatever services are needed. This will require an ongoing effort for as long as you live in your own home.
- You will also need to be more vigilant about health changes. Medical clues that might be readily observed in a nursing home will be your responsibility.
- Quality and reliability of service providers is obviously a critical factor. Full-service health care agencies should be accredited. If you are dealing with another

kind of provider, ask if it is licensed, and about background checks or bonding of employees. Find out who is liable if an employee is injured in your home; ask about the kind and frequency of training and supervision. Ask who you would get in touch with if you had a complaint. Find out whether you can get a different caregiver assigned with or without cause; find out if there is a 24-hour emergency number. And just ask around, to see if anyone you know has a recommendation or a warning (ask doctors and nurses you know, clergy, friends; check at the local senior center). And if you don't know anyone who has used a particular service, ask the provider for a list of customers in your neighborhood whom you can check with.

- If you are financially needy, in-home care is not officially available through Medicaid, but most states now grant waivers to permit this as an alternative to residential nursing care. However, such programs generally have limits on the kinds and amounts of services you can receive, and the circumstances under which you qualify. They typically also have a limited ability to administer such waivers, and there may be a waiting list. Check with the Medicaid office in your state.
- Medical insurance generally will not cover home health care services, or will do so only for a limited period of time. If you have long-term care insurance, it may or may not cover home care, or may kick in only under fairly stringent circumstances. So check your eligibility before making any decisions. Medicare may cover some home medical care services that you need, but it generally will not cover help with activities of daily living.
- Costs add up quickly. The 2014 national average was \$20/hour for *non-Medicare-certified* home health aides. The average rate for adult day centers is about \$65 *per day*. However, many government, community, religious and philanthropic care providers have sliding fee scales so you might pay a lot less than the going rate, if you have low income.
- If you hire individuals rather than companies to perform services for you, you will have to pay the "nanny tax" for anyone receiving total annual wages from you above \$1900 (in 2014 so the number is adjustable annually for inflation). You have to pay either the full 15.3% extra Social Security and Medicare taxes, or else pay half and withhold the other half from your employee's pay. You could also have federal unemployment taxes to pay.
- Even if the person(s) coming into your home are highly recommended or even bonded, you are still letting in a stranger who might be tempted to take advantage. It is prudent to keep valuables well hidden or preferably locked up. Check receipts if someone else is making purchases in your name, to make sure that you are paying only for what's yours. Don't give anyone your credit card, or carte-blanche access to your checkbook.
- When comparing costs, don't forget to take into account what it costs to own and run your home, and the capital you have tied up in it. If your home will need modifications such as wheelchair ramps, stair elevators, wider doorways, handi-

capped-accessible bathrooms, don't forget to take these costs into account as well. Also consider whether, in your neighborhood, these changes will make your property more saleable or less saleable later on.

## **Option 2: Moving to a different house or apartment**

### *Advantages:*

- Same as Option 1, *plus*:
- You can choose the place that most exactly fits your preferences in terms of location, space, amenities, comfort, and whatever other factors matter to you.
- If you move to a smaller place, you will probably free up some home equity and/or reduce ongoing expenses, which will help you pay for extra services.

### *Things to watch out for:*

- Same as Option 1, *plus*:
- Are you likely to be healthy enough long enough to make this move worth the trouble and expense?

## **Option 3: Living with someone else**

### *Advantages:*

- Same as Option 1, *plus*:
- Two (or more) can live cheaper than one. Adult foster care or group homes for the mentally or physically disabled can be economical alternatives, and in some cases costs will be paid in full or in part by the government.
- You receive increased companionship.
- The person(s) you move in with will probably already be taking care of basic home needs (housekeeping, outdoor maintenance, etc.), burdens you may no longer be able to handle yourself. In addition, they may be able to provide additional caregiving for you or at least be a backstop in case outside care providers let you down occasionally.

### *Things to watch out for:*

- Same as Option 1, *plus*:
- You will have less (probably much less) privacy and control, living with someone else. Worst case: you could get kicked out, and have to find someplace else to go on short notice.
- Personal dynamics can be tricky. It's hard living with other people, whether family, friends or strangers. Existing relationships can get strained to the breaking point. New relationships can be disasters. Any arrangements should be made explicitly on a trial basis, with other alternatives ready.

## **Option 4: Moving to an assisted living facility**

### ***Advantages:***

- All kinds of facilities are available: apartments, condominiums, single-family homes, units in duplexes or multi-family homes or in low-rise or high-rise buildings. You can have a rural, suburban, or urban setting. You can get luxurious or plain accommodations. You should expect on-duty staff 24 hours a day, supervision of staff services (i.e., you don't have to find and oversee your own service providers), health services and medication management, recreational and social services, meals, and housekeeping, laundry, and transportation services. You may also be able to find almost anything else you can think of. Do you want to be allowed to smoke or drink? Want to keep a pet? Need a kosher kitchen? Want to take college courses? There are places for you!
- Assisted living facilities generally emphasize independence, privacy, and personal dignity. Help is there for you, but only what you want, when you want it. Family and community involvement are usually encouraged as well, so you can more easily have as well-rounded a life as you desire and are capable of.
- You will probably have more opportunities for social interaction, even though you may be leaving your old neighborhood. Chances are, most of the other residents will be about your age, and some of them will be about your speed, whatever speed that happens to be. Most facilities offer many opportunities to mingle, whether for group activities or for meals or lounging.
- Although you pay quite a bit every month, you generally do not have to pay property taxes, nor do you pay for maintenance, repairs, or general upkeep (raking leaves, shoveling snow, etc.). You do generally have to pay for renter's insurance for your personal belongings, though, if you want it.
- Assisted living is usually much cheaper than nursing home care. It can also be cheaper than staying home and paying for services to be brought to you, if you need a fairly high level of help. This is because a centralized facility can provide services more economically.
- Some assisted living and continuing care facilities have special wings for patients suffering from Alzheimer's or other forms of dementia, and can provide the special supervision required.
- If you are moving to this kind of facility mainly for medical purposes, most of your costs may be tax deductible as a medical expense. If a child or other relative is paying for more than half the cost, your costs may be deductible on his or her taxes. Consult your tax advisor.

### ***Things to watch out for:***

- If you need skilled medical care on a daily basis, you should probably be looking for a nursing home rather than an assisted living facility (although some places offer both). Assisted living assists you, but is not intended to provide intensive care or round-the-clock supervision. (Exception: as mentioned above, people with Alzheimer's or similar disorders who otherwise are reasonably healthy may

be suitable for assisted living, but only in facilities that are specially staffed for them.)

- Costs are moderately high, and vary a lot. The latest survey (by Genworth Financial, in 2014) shows a national average basic cost of \$42,000/year for a private room in an assisted living facility. Costs in urban areas are usually quite a bit higher than in rural areas. So you might want to consider living in the country ó especially if you have children or other important people in your life who live in separate populated areas, and you can find a place comfortably between them.
- Retirement communities and facilities vary enormously in what they offer, and in levels of comfort and style. Shop around, and look for a place that offers mainly what you need and want, so you are not paying for amenities or luxuries that you can easily do without. Even when it comes to services, make a distinction between what you really need and what you would merely like, so you don't pay too much for things that are not that important to you, or that you or others can easily provide for yourself.
- Unlike continuing care retirement communities, assisted living facilities generally do not require big up-front payments, but financial arrangements are highly variable, so make sure you understand the payment structure and what you are getting. There are three common arrangements: (1) a flat rate each month; (2) a multi-tier arrangement where increasing levels of service (particularly higher levels of medical care, if and when you need them) kick you into a higher payment bracket; or (3) base-plus arrangements where you pay a base fee plus add-on fees for the specific services you use. When you are asking about costs for services, you might want to bring along the service cost checklist provided by the National Center for Assisted Living, along with their other useful materials, available at: (<http://www.ahcancal.org/ncal/resources/Pages/ConsumerResources.aspx>).
- Medicaid typically will not cover this kind of facility, if you are currently needy or if you run out of money later. Although many states do offer Medicaid waivers to fund assisted living, availability is limited, and you need to check with your state office to see whether you can actually receive such a waiver. If you start out paying your own way and then run out of money, you will probably have to leave. If you are eligible for Supplemental Social Security, that may cover some costs.
- If you have a private or employer-sponsored long-term care insurance policy, it may or may not cover this kind of arrangement (watch out especially for nursing home-only policies, home health care-only policies, or any policies issued before 1997).
- This is where you will live, so you need to be comfortable that you like the location, the style, the staff, and even the other residents. Before you make a final decision, spend some time there, talk with people, and ask some of the current residents how they like it. Try showing up unannounced on a weekend, when sales staff is probably not around, and look around on your own. You may be surprised what you find out!

- Make a checklist of questions you want answered. Some of the answers can be supplied by the facility administrators. Others you can obtain by making your own observations, or by talking with current residents. Think of any amenities, services, or living conditions that are important to you. Then add them to the checklist offered in the "Choosing an Assisted Living Residence: A Consumer's Guide" available from the National Center for Assisted Living at: <http://www.ahcancal.org/ncal/resources/Pages/ConsumerResources.aspx>; or the Assisted Living Federation of America's checklists on choosing a facility at [http://www.alfa.org/alfa/Checklist\\_for\\_Evaluating\\_Communities.asp](http://www.alfa.org/alfa/Checklist_for_Evaluating_Communities.asp), or the various free checklists that are available from the Caregivers Library at <http://www.caregiverslibrary.org/Default.aspx?tabid=70>.
- If nursing care is provided as you age, you need to take into account the quality of that component. See the following section, relating to nursing homes, for guidance in evaluating providers of that level of care.
- Assisted living facilities are subject to very little federal regulation. Different states take different attitudes toward regulation and enforcement, so you may have to be your own watchdog!
- The facility contract (or Resident Agreement, as it is sometimes called) is very important. It is a legal contract. Have your lawyer look at it, and don't sign it unless you are comfortable with all of the provisions. There should also be a written Service Plan – whether your state mandates this or not. This agreement spells out what services you need or want, and in what manner they are going to be provided – ideally drawing in other family, medical providers, and perhaps outside services as well. Compare these agreements with the information you were told when you brought your checklist along – if anything doesn't match up, challenge it.

### **Option 5: Entering a nursing home or hospice**

#### *Advantages:*

- If you need a high level of nursing care, especially if 24-hour supervision is required, a nursing home can be the most practical and economical option. You have a variety of choices from hospital-based nursing facilities, through non-hospital nursing homes, intermediate care facilities and, if medical needs are light, custodial care facilities (rest homes, group homes, etc.).
- Social life tends to be less active, of course, than in assisted living facilities, but there are usually better social opportunities in nursing homes than in private residences, at least if you need skilled care.
- If you are in the last months of your life, a hospice usually can provide the medical care you need along with a comfortable and caring environment. Both professional and non-professional staff is trained to work with people who are facing death, and you are much more likely to get the emotional support you need. Note that these days a majority of hospice care is actually provided at home.



- Nursing homes usually don't have a big up-front cost. They are not allowed to ask for large lump-sum payments as a condition for admission, although they may still require a one- or two-month security deposit.
- If you need nursing care but cannot afford it, Medicaid will pay. That's the good news. The bad news is that you do not get to choose where you will live ó Medicaid will place you in the first bed that becomes available in your area. However, if you are already in a nursing home and then run out of money, you can generally stay where you are ó neither the nursing home nor Medicaid will require you to move somewhere else. So there is a big advantage in finding your own nursing home while you still have some money left and can pay your own way for a while. However Medicaid will probably move you from a private room, if you have one, to a shared room.
- Costs are generally 100% tax deductible (after you pass the 10% Adjusted Gross Income threshold).

***Things to watch out for:***

- Even when nursing home care is the only practical alternative, it can feel like abandonment or even imprisonment. With luck you or your loved one has a more open attitude than that, and the facility you find will end up being better in some ways than you might have expected. Still, it is a difficult change to make. If one of the other alternatives can be worked out, the emotional strain on everyone might be less, and this could be worth a lot. Naturally, the weight of this factor depends on the attitudes of and relationships of everyone who is involved.
- Nursing care is expensive. The national average cost for a private room in 2014 was \$87,600/year ó and quite a bit more than that in urban and high-cost areas. You can find lower costs in two ways: (a) rural areas can often offer very good care at much lower cost, saving you sometimes a quarter or a third off the price; and (b) you can get a semi-private room instead of a private room, which will typically save you about 10% on the cost.
- Nursing care (whether at home or in a nursing home) and hospice care usually receive only limited coverage, or none at all, in health insurance plans ó and this means Medicare, as well as private plans. Separate ólong-term careö policies are needed. Of course, once you need such care, it is too late to get insurance. But make sure you understand how much, if any, insurance coverage you do have when making your decision. Consult your Medicare office or private insurer.
- Think about what is important to you, then make a detailed list of things to watch for and questions to ask about nursing homes you are considering. For a very good sample list, go to: <http://www.medicare.gov/Nursing/Checklist.pdf>.
- Quality of care is important, of course, so be sure to check out the publicly available reports (see the For More Information section, below).
- A personal visit is critical, and don't just take the official tour. Show up at meal-time and/or on a weekend, when there is a lot of action or the staff may be short-handed, to see how they deal with those situations. Many nursing homes will let

you and perhaps a family member stay overnight ó take advantage of this opportunity, if it is available (and if it isn't, ask why not). If you have a friend who is a nurse, ask her or him to make an "unofficial" visit, too.

- You will need to review the nursing home contract carefully. It is no longer legal for them to require a spouse or a child to pay as a private patient in order for you to be admitted, nor is it legal to require the family to pay if you run out of money. Compare the contract with the information you were told when you brought your checklist along ó if anything doesn't match up, challenge it.
- Nursing home residents are more susceptible to neglect, improper care, or even abuse and crime than people living in other situations. Extra vigilance will be required.

### **Making the decision**

Families sometimes are too eager to make decisions on behalf of their elderly members. As much as children do care about the welfare of a parent, for instance, they can be too quick to "solve" the parent's problem at a time and in a fashion that the parent is not really comfortable with. In the end, the decision properly belongs to the person whose life is changing. Although this can be frustrating for others who might want to "get things settled" faster or differently, those feelings should not be given too much rein.

There are exceptions, of course:

- If the elder is mentally incompetent, then of course someone else has to be in charge. Even so, there should be due recognition of the personality and known preferences of the person in question.
- Who pays the piper, calls the tune. If a child or several children, for example, are paying the lion's share of a parent's costs, then this gives them additional latitude. Again, though, this latitude should be limited. It should especially be limited if the financial assistance was not asked for, but voluntary. Even if asked for, the person receiving help should be given as much dignity and control as possible. And it is worth adding here that the interests of heirs are not a legitimate consideration. An elder always has first claim on his or her own assets. The hopes and expectations of children or other heirs should rarely be an important consideration, and a child is not "paying for" a parent's care just because the parent is "spending the child's inheritance."
- If the solution is to for the elder to move in with a child, a sibling, or someone else, all the members of that household do have a legitimate say in the timing and all of the other arrangements that affect the household.

Even with these caveats, though, it is important to remember that this is often a difficult time for the person who can no longer live alone. At the very least, there will be big changes in his or her life. At the very least, he or she is experiencing a loss of physical or mental competence and a sense of reduced control ó and probably an increased sense of the closeness of death. The whole experience is likely to be disturbing, even depressing. It is important that family members not make it worse.

## **For More Information**

Go to the RetirementWORKS® Retirement Readiness page on [Caregiving](#). This page provides links to helpful resources in addition to those mentioned elsewhere in the present document.