

# Home Care: A Family Caregiver's Guide

## What Is Home Care?



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Home care can help people who have just come out of the hospital or rehabilitation facility and need some help while they get well enough to manage on their own. Home care can also help people who are disabled or have chronic health conditions. A special program called hospice provides care at home for people who are near the end of life.

Home care services can offer you and your family member trained help with medical and personal care. Keep in mind, though, that home care is not a cleaning service. It also does not provide people to run errands for you and your family member or to do other jobs like babysitting.

## Who Provides Home Care Services?

Many health care professionals provide home care services.

Here are a few:

**Nurses** perform many important medical tasks. They change dressings and clean the wound for a patient who has just had surgery. They keep records of blood pressure and other vital signs, look for changes in the patient's condition, and check the patient's medications.

**Physical therapists (PT)** help a person get stronger. They show a person who is weak or disabled how to get out of bed and move to a chair. They show the person how to do some strength and flexibility exercises. The PT can help you decide if your family member needs special equipment, such as grab bars and guard rails. They can also arrange to have them installed.

**Speech therapists** work on language skills, like helping a person recovering from a stroke to speak clearly again.

**Occupational therapists (OT)** help people relearn skills like how to feed and dress themselves.

**Social workers** help you apply for benefits and offer advice about services like adult day care or respite (time off for the family caregiver). They can also talk to you about your worries and other problems.



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## What Is the Difference between Skilled and Custodial Care?

“Skilled” and “custodial” care are terms that come from government programs like Medicare and Medicaid and private insurance companies.

They divide care into two types:

**Skilled care** is care provided by a nurse, physical therapist, occupational therapist, speech therapist, or social worker.

**Custodial care** is provided by a home health aide or a home attendant. (This guide will use the term “home health aide” or just “aide”.)

Doctors order **skilled** services when they decide it is medically necessary. If your family member needs skilled care, he or she may also qualify for some custodial care. Insurers will cover custodial care only if your family member is receiving skilled care. They do not cover custodial care by itself.



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Home health aides (custodial care) are allowed by law to do only certain health care tasks. They can take the patient's temperature and check blood pressure. They can change a dry dressing (one that is not oozing blood or pus) and help the patient do range-of-motion exercises, such as simple stretches and moving arms and legs. They can also bathe, dress, and feed patients, cook light meals, do the patient's laundry, and help the patient to walk. They are not usually allowed to give a patient medicine. However they are allowed to bring medicine to the patient and help them open the bottle.

Also, an aide is not allowed to provide services for the entire household. Many people think that custodial care does not require much skill. That is not the case. Some tasks can be very difficult, such as bathing a person with dementia or moving a very heavy patient.

## Who Pays for Home Care Services?

Medicare, Medicaid, or private insurance will usually pay for services provided by a nurse or therapist ordered by a doctor. But insurance will probably not pay for all the care your family member will need. The rest of the care will have to come from you or other family members. You may also decide to hire people on your own, using your own or your family member's money to pay them.



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**Medicare**, which is a government program for people over 65, and those under 65 who have a disability, may pay for the home care services your family member needs on a short-term basis (usually weeks, not months).

**Medicaid**, which is a government program for low-income people, covers long-term home care services. However, each state decides who is eligible and which services it will pay for. To find out more about Medicaid guidelines, you can ask a social worker or contact your local social services office.

**Medicare and most private insurance plans will pay for home care services if the patient meets the following conditions:**

- ▶ Has a written order from your family member's doctor for home care services



Many insurance plans cover home care visits. Some will cover more services than others, but in general, services are very limited. Unless you are able to pay on your own, you should not expect 24-hour care.

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- ▶ Is homebound (this means it is very hard for him or her to leave the house)
- ▶ Needs only some short-term or part-time nursing or therapy services

You may want or need certain home care services for your family member, but insurance may not cover some or all of them. There is also a shortage of trained workers, which may affect the number and type of services you are able to get.

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## Referral to a Home Care Agency

Let's say your family member is in a hospital and has Medicare or Medicaid, and the doctor says that your family member needs home care. The discharge planner (nurse or social worker) will probably refer you to a Certified Home Care Agency in your area. If your family member has private insurance, the discharge planner will refer you to an agency that the insurance company works with.

## Mutual Care Agreement

Before accepting your family member's case, the home care agency might ask you to sign an agreement. This agreement usually states that you, or another "responsible person," which means an adult who is able and willing, be available:

- ▶ to direct the home care workers if your family member cannot do it.
- ▶ serve as backup in case the scheduled worker, or a substitute worker, is unavailable.
- ▶ organize, prepare and give your family member his/her medications.
- ▶ perform certain treatments. Those treatments will be decided once your family member's condition and care needs are assessed.

If you refuse to sign this contract, the agency might refuse to take your family member's case. But, if you cannot perform any of these duties, it is important that you let the person who is making the referral and the agency know. There may be other options.

## What are the Different Types of Home Care Agencies and How Do I Choose One?

There are different kinds of agencies.

A **Certified Home Health Agency (CHHA)** is licensed by the state and certified by Medicare and Medicaid to provide skilled care. These agencies also provide custodial care either by their own staff or by another agency with which they have a working arrangement.

A **Licensed Home Care Agency** is licensed by the state and provides aides who assist with personal care, transportation to appointments, and household tasks. Some Licensed Home Care Agencies also provide nurses and other skilled staff.

Some states keep a database, or registry, that has lists of nurses and home health aides. You can call these registries and ask for a list for your location, or the information may be available on the Internet. In some states, these registries are regulated and licensed. When using these registries, caregivers should ask specific questions about worker training and qualifications. Check your state's Department of Health website to see if there is a registry.

If your family member still needs help from a home care agency after the insurance runs out, you may want to keep using that agency and pay them directly. Or you can ask friends and family members if they know of any good agencies you can use. Remember that other people's good or bad experiences may not be the same as yours.

You can also go to the Certified Home Health Agencies (CHHAs) database on the government website [www.medicare.gov/HHCompare](http://www.medicare.gov/HHCompare) and compare agencies. This will give you basic information about what services agencies provide and the number of patients who either improved or needed to go into the hospital. The site does not offer much help in learning about other things that will be important to you, like how reliable and friendly an agency's aides might be when caring for patients.

## What Questions Should I Ask a Home Care Agency?

When you interview an agency, ask these questions:

- ▶ What types of services do you provide?
- ▶ What tasks can your staff perform?
- ▶ Do you train your aides?
- ▶ What hours do they work?
- ▶ What type of medical insurance do you accept?
- ▶ How much do you charge per hour?
- ▶ How and when do I pay you?
- ▶ Can your agency arrange for medical equipment when needed?
- ▶ Do you screen aides before you hire them?
- ▶ Do you conduct a background check?
- ▶ Do your aides have special training to deal with medical conditions like dementia, paralysis, or stroke?
- ▶ How do you handle complaints?
- ▶ Do you provide 24-hour access in case of emergencies?



Remember that when you hire an aide on your own, you also take on the role of supervisor and financial manager.

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## Should I Hire an Aide Who Does Not Work Through an Agency?

You may need or want to hire more home care help than your insurance company will pay for. Or you may need help once the insurance coverage ends. In these cases, you will need to pay from your own or your family member's money.

Remember that when you hire an aide on your own, you also take on the role of supervisor and financial manager. You might not have backup when she or he calls in sick or has a personal emergency. With notice, you may be able to hire a substitute, but often these schedule changes happen at the last minute. It can upset your and your family member's routine. These issues can be solved, but just keep them in mind if you are thinking about hiring someone on your own.

You may know someone reliable who can do the job and who already knows your family member. Or you can advertise in a neighborhood newspaper or in an on-line service, or ask for names from friends and coworkers. Be sure you screen all applicants on the telephone by telling them about your family member, the kind of help you need, and the basic description of the job. You can then interview in person only those who seem right for the job.

**Ask for identification and references. Be sure to call these references and ask about the person's work habits, attitude, and reliability.** Make a list of tasks you want the home health aide to perform, and make sure she or he has the training or experience for those tasks. For example, if your family member has memory problems or tends to wander, you will want to make sure the aide has training and experience working with this kind of person. You will also want to make sure the aide is patient and will not get annoyed at your family member's behavior. If the aide's tasks will include driving your car, check with your insurance company to make sure your vehicle is covered in case of an accident. If the home care aide will be driving his or her own car as part of the job, make sure that the car is safe.



Whether you hire agency staff or privately paid workers, make sure ahead of time that you understand each person's role. Know what each person can and cannot do.

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## What Should I Know about Working with a Home Health Aide?

Whether you hire agency staff or privately paid workers, make sure ahead of time that you understand each person's role. Know what each person can and cannot do. You also want to be clear about what you can and cannot do. For example, you will need to find a balance between family privacy and outside help, and this can be hard to do. Each situation is different, and you will need to work out the details.

Keep a record of when nurses, physical therapists, social workers, and other specialists are coming to the home. If at all possible, plan to be there at the same time, at least in the beginning. This gives you a chance to watch what they do, ask questions, and learn the tasks that you may be doing later on. Keep their phone numbers handy so you can call them to ask questions, report any changes, or discuss problems.

In general, aides will spend more time with your family member than nurses or physical therapists will. When a home health aide comes to your home the first time, plan to spend some time together. Show her or him around, and explain the routines your family member prefers. If you do not live in the same household as your family member, you may want to call during the day to check in and see how things are going. Also plan to drop in from time to time without calling ahead.

Some other things to think about:

- ▶ **Terms and expectations:** If you hire privately, be clear about what you expect. Write these things down in a simple contract. Include the hours and pay you have agreed on, who pays for meals, how much vacation time is included, and a backup plan in case the aide cannot arrive on time or has to cancel. These situations do come up, but if you have a backup plan, you will be better able to make other arrangements. If you are using an agency, make sure you understand its terms.
- ▶ **Valuables:** Just as you would with any stranger or worker entering your home, put away private papers, cash, and valuables in a safe place.

- ▶ **Emergencies:** Leave a list of emergency phone numbers, including your family member's doctor and all your phone numbers. Put the list where anyone can easily find it. Develop an emergency plan, and make sure everyone knows it. If you are using an agency, you should ask about their emergency policy. For example, when is an aide supposed to call 911?
- ▶ **Aides' personal relationships:** Agency staff are not allowed to have visitors. If you are hiring aides on your own, you should discuss whether they may have visitors. Also discuss any other personal issues that might interfere with their providing care to your family member.

## What Kinds of Problems May Come Up and How Can I Solve Them?

**Regular meetings and open communication can help solve problems before they arise.**

Two of the most common problems are resistance to outsiders and cultural differences.

### Resistance to Outsiders

Many older people resist the idea of people they don't know coming into their home, and this may include home health aides. They may insist they don't need this care, that they are perfectly able to take care of themselves, and that you, as their relative, are the only person they trust. If this problem is not resolved, your family member may fire the workers, or make it so difficult for them that they quit.

Some of this resistance comes from the fear of theft, abuse, and other harms. Most of it, however, probably comes from the fear of losing one's independence. This is common, and there is no simple solution. You can, however, talk to your family member about the tasks for which no help is needed. Tell your family member that having this help will actually allow him or her to do more and may prevent future health problems.



Your family member's resistance to home care may be from fear of losing independence.

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You can also remind your family member of your other responsibilities. Your job, your family, and your children need you too. Explain that the aides make it possible for you to be both a good daughter or son and a good parent (or whatever the combination of relationship is). You should not feel guilty if you cannot provide all the care. And you should not assume that you can provide all the care for a long time, no matter how much you may want to or feel that you should. It will not help your family member if you are exhausted, anxious, or overwhelmed.

Experienced home health aides know how to handle patients who do not want their help. They do not take rejection personally. Some will be firm, while others will gently distract the patient. You may need to try several aides to find one whose style works best with your family member. Sometimes what starts out as a bad situation will work out very well as the family member and worker learn to understand and appreciate each other.

### Cultural Differences

Cultural respect between the home health aide and your family member is really important. Start with names. Ask the aides if they want you to use their first name or last name – “Mary” or “Mrs. Jones.” At the same time, tell them what you and your family member want to be called. Some people are quite casual about this. Others, particularly older people, do not like to be called by their first name. They may not like to be referred to as “Sweetie” or other baby names. Many problems can be avoided if cultural differences are dealt with up front. Often, though, they only come up after a problem has occurred. Many aides are women from minority or immigrant groups. So are many of the patients they care for. If your family member does not speak English, ask for an aide who speaks the same language. Many aides who speak a different language at home can speak and understand English well enough to talk to your family member. If the situation does not work, then you will need to hire a different worker.



Cultural respect is important to everyone. Make sure you discuss language, food, and other differences in advance

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Language is only one possible issue. Other differences can come up that have to do with food, **religious practices**, or daily routines. If you and your family member follow certain religious or other practices, you need to explain those to the aides. They may have cared for other patients of your religion and may assume your practices are the same when, in fact, they are not. At the same time, you should ask the workers if there is anything you should know about their culture and religious practices—things that can affect their ability to work. Having respect for each other’s cultural differences can actually create a bond between the worker and the family member.

**Good nutrition** is essential for good health. As people age, they sometimes find that the foods they used to enjoy don’t taste good anymore. Or they may be sensitive to unfamiliar smells. If the home care aide cooks food that is too spicy or has a strong smell, your family member may refuse to eat it. In this case, you will need to work with the aide and your family member to come up with a food plan that they both agree on.

Finally, keep in mind that the relationship between you, the aides, and your family member is a business relationship. You both may grow close to the aides, and that is fine, but it is still a business relationship. **Aides are hired to perform a service. Do not expect them to do more than they are allowed or prepared to do.** Know where to draw the line, even when that line is not obvious. You need to be clear about what behavior you consider off limits.

## Conclusion

Home care can make a big difference in your life and in the life of your family member. **Being a family caregiver does not mean that you have to give up everything and everyone else. But home care does take work on your part. You need to set up a good plan, make sure it is working, and then watch carefully to see when changes are needed.**