



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 limited to specific tasks.

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## Home Care: A Family Caregiver's Guide

Many people receive care at home for illnesses, recovery from surgery, disabilities, and other conditions. Home care comes in many different forms, depending on the situation. The choices can be confusing. This guide describes the types of home care, the roles of home care workers, the basics of insurance coverage and private payment for home care, and much more.

Home care, like much of health care, is changing rapidly. This guide is intended to provide basic information; your family member's situation (care needs, insurance, location, etc.) will determine what services are available.

Once you read this guide, we encourage you to read its companion guide, "[Working with Home Health Aides.](#)"

### Types of Home Care

There are, in general, two kinds of home care: "skilled" and "personal." These terms come from government programs, like Medicare and Medicaid, and private insurance companies.

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

**Personal care** is provided by a home health aide, or by workers called home attendants, personal care attendants, or aides.

Companion and homemaker services, a third type, provide nonmedical care.

## Who Provides Home Care Services?

Many different people 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. They also develop a care plan.

**Physical therapists (PTs)** help a person get stronger. 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 (OTs)** help people re-learn skills like how to feed and dress themselves. They show a person who is weak or disabled how to get out of bed and move to a chair.

**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.

**Home health aides** and **personal care attendants** primarily provide personal care, which includes assistance with eating, bathing, dressing, and walking, as well as activities associated with living at home, such as shopping, meal preparation, and doing laundry.

Home health aides are allowed to do only certain health-related or personal 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 are not usually allowed to give a patient medicine; each state has different rules regarding what an aide can do.



Although the federal government has guidelines for training of home health aides, each state has its own system for home health aide education and certification. For a state-by-state list of training hours, see <http://phinational.org/policy/states>. Most states do not have any requirements for personal care attendants.

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Be aware that a home health aide is usually only in the home to provide services to the patient, and is not supposed to provide services for a spouse or for other members of the household. If you pay privately, you may assign tasks that include other members of the household. (Some managed care companies will include care for a child if the patient is the head of household.)

Personal care attendants share many of the same duties as home health aides. The differences between home health aides and personal care attendants depend on each state's requirements for training.

Many people think that personal 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 (transferring) a very heavy patient.

**Homemakers** can assist your family member with light housekeeping, laundry, grocery shopping and food preparation, and other household tasks that would enable your family member to remain at home. Homemakers do not generally provide personal care and are not maids. Heavier tasks and full household cleaning are not usually performed by a homemaker.

Read "Working with Home Health Aides" for additional guidance on how to work effectively with home health aides, personal care attendants, and homemakers.



While they are all "home care" agencies, the agencies that provide skilled care (nursing and rehabilitation) are generally called "home health" agencies.

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## What Are the Different Types of Home Care Agencies?

There are different kinds of agencies.

A **Home Health Agency (HHA)** is licensed by the state and certified by Medicare and Medicaid to provide **skilled** care. These agencies also provide personal care either by their own home health aides or by aides that work for another agency with which they have a working arrangement, such as a home care agency.

A **Home Care Agency** provides home health aides, personal care attendants, or homemakers who provide **personal** care, transportation to appointments, and household tasks. Some home care agencies also provide nurses and other skilled staff. Home care agencies may be contracted to provide personal care through Medicaid for someone who needs care at home for a

long period of time. Some states require home care agencies to be licensed if they participate in Medicaid.

A **non-medical or companion agency** is usually not licensed or covered under insurance (long-term care insurance may be an exception). Some workers may be trained home health aides, but it depends on the individual worker. Frequently, non-medical agencies are small, locally run businesses that are franchises of large companies with brand names.

**Employment or registry agencies** provide names of people available to provide home care. Your family member's state may also maintain a registry. This can often be found through the state's Department of Health.



When Medicare, Medicaid, or private insurance pay for home care services, they will probably not pay for all the care your family member will need.

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## Who Pays for Home Care Services?

### Skilled Care

Medicare, Medicaid, or private insurance will usually pay for skilled services provided by a nurse or therapist through a HHA when ordered by a doctor. Be aware that insurance will probably not pay for all the care your family member will need.

**Medicare**, which is a government program for people 65 and over and those under 65 who have a disability, may pay for home care services – but only for the period that your family member needs skilled services (usually weeks, not months). Medicare Advantage plans, which are provided through private insurance companies, may have different rules from “original” Medicare, and may have case managers who can assist you.

**Medicare and most private insurance plans (including supplemental and “Medigap” plans), will pay for home care services if the patient meets the following conditions:**

- ▶ A doctor confirms in writing that he or she has examined the patient within 30 days and that the patient needs skilled nursing care. Without this signed paper, the home care agency cannot “open the case” (begin treating your family member). The doctor signing this paper can be a hospitalist or community-based doctor who has seen your family member within the past 30 days.
- ▶ The patient is homebound. (This means it is very hard for him or her to leave the house.)



Medicare and supplemental insurance plans will cover personal care only if your family member is receiving skilled care. They do not cover personal care by itself.

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- ▶ The patient needs only short-term or part-time skilled 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. (For other rehabilitation options in facilities and from home, see the Next Step in Care guide "[Planning for Inpatient Rehabilitation \(Rehab\) Services](#)").

*Changes in Medicare practice:* Until a federal court ruling in January 2013, some providers incorrectly told patients that Medicare would not pay for rehab unless there was continued improvement. Now, rehab in a skilled nursing facility, outpatient setting, or by a home care agency can continue if the patient's functional abilities would deteriorate without continued skilled therapies, until the dollar "cap" (limit) for that therapy is reached. When that limit is reached you can apply for an exception based on the patient's continuing need. Some exceptions are automatic; others need to be documented. Since many providers are still unaware of this ruling, you may have to be a strong advocate to get continued therapy for your family member. See the Center for Medicare Advocacy website for information on the Centers for Medicare and Medicaid Services regulations: <http://www.medicareadvocacy.org/medicare-info/improvement-standard/improvement-standard-update-cms-revises-medicare-policy/>.



Medicaid long-term care programs could see major changes during the next several years. With federal and state efforts to control costs, there may be changes in eligibility, services, and management of care. If your family member receives long-term care services or supports through Medicaid (such as home care), be alert for notices of upcoming changes.

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**Medicaid**, which is a government insurance program for low-income people, may pay for skilled home care services if your family member qualifies. Each state has different types of Medicaid, and what Medicaid will pay for depends on your family member's specific plan.

### Personal care (without a skilled service)

Medicare and most supplemental plans will **not** pay for personal care alone.

**Medicaid** may pay for personal care services. However, each state decides who is eligible and which services it will pay for. Each state has different types of Medicaid programs for people who need care at home for a long time (called Home and Community-Based Services). Some states have long-term care programs

through Medicaid that provide case managers and other services to help organize care. These include a type of program, available in some states, called Medicaid Managed Long-Term Care. To find out more about Medicaid guidelines in your family member's state, you can ask a social worker, contact the local Area Agency on Aging office, or contact the local or state Medicaid office.



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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**Long-term care insurance** is a privately paid insurance plan specifically covering long-term needs, such as personal care. Most long-term care policies cover a portion of institutional care, such as an assisted living residence or nursing home. Some also pay for services in the community, such as home care and adult day services. Care may be limited, based on the specific plan.

**Local Area Agencies on Aging** may have funding for personal care services and case management, depending on your family member's circumstances.

### Homemaker services

**Local Area Agencies on Aging** or **charitable organizations** may offer homemaker services, possibly with a sliding scale or co-pay based on your family member's financial situation. In some states, **certain Medicaid programs** may also pay for homemaker services.

## 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 home health agencies in your area. If your family member has private insurance, the discharge planner can refer you to agencies that the insurance company works with.

You do have a choice of agencies. The possible choices may depend on your family member's insurance, care needs, or location. (One consideration: Can home care workers easily travel to your family member's home?)

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

Whether you are paying privately or using insurance, you should ask these questions:

- ▶ What types of services do you provide?
- ▶ What tasks can your staff perform?
- ▶ Do you train your aides? How often? On what topics? What kind of testing is done to see if the aides have learned to do the tasks?
- ▶ Do your aides have special training to deal with medical conditions like dementia, paralysis, or stroke (or other conditions that apply to your family member)?
- ▶ What kind of supervision do your aides receive? How often does the supervisor come and observe the aide's work? What hours do they work?
- ▶ Do you screen aides before you hire them? How?
- ▶ Do you conduct a background check? What exactly does that background check include? Is the criminal background check for this state only, or is it nationwide?
- ▶ Do you test your aides for drugs? How often?
- ▶ Are your aides insured and bonded with your agency?
- ▶ What type of medical insurance do you accept?
- ▶ How much do you charge per hour?
- ▶ How often do I pay you? Do you take credit cards?
- ▶ Can your agency arrange for medical equipment when needed?
- ▶ How do you handle complaints?
- ▶ Do you provide 24-hour access in case of emergencies?

You can also go to the home health agencies 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.

## After an Agency Is Chosen

The home care agency will schedule a first visit where a nurse will evaluate your family members' condition and determine the type and amount of services that will be provided.

- ▶ You should plan to be present during the first home care visit. You can provide important information in the evaluation process, ask questions, or express your concerns if you disagree with the evaluation.

The home care agency will then ask your family member's insurance company to authorize services. The insurance company may authorize all services requested, some or none, depending on the specific policy. If you disagree with the insurance company's decision, you should ask about the appeal process.

If no insurance is involved (paying privately), then no authorization is needed.

## 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 a "responsible person" (you or another adult who is able and willing) will be available:

- ▶ To direct the home care workers if your family member cannot do it.
- ▶ To serve as backup in case the scheduled worker, or a substitute worker, is unavailable.
- ▶ To organize, prepare, and give your family member his/her medications.
- ▶ To 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.



## Keeping Track

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.

## Can I be Paid to Provide Home Care to My Family Member?

**State programs:** Some states have programs that help people pay for the caregiver of their choice, and in certain circumstances that can be a family member. These programs – called, variously, "consumer-directed," "participant-directed," "cash and counseling" or other titles – differ enormously depending on where you live. Most have income and other eligibility requirements that the care recipient must meet, and strict rules often apply as to who can be paid for the caregiving. For information about what's available in your state, contact your local Medicaid or aging services department or go to the National Resource Center for Participant-Directed Services (<http://www.bc.edu/schools/gssw/nrcpds>).



Be aware that there are often waiting lists for these programs and that states have been cutting back on them because of budgetary pressures.

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**Veterans' benefits:** A law passed in 2010 provides a monthly stipend to primary caregivers of veterans injured in military conflict after 9/11/2001. Other benefits to caregivers include travel expenses, access to health care insurance, mental health services, and respite care of 30 days a year. For more information, call 1-877-222-VETS (8387). Caregivers of veterans of other wars may be eligible for the Veterans Administration's Aid and Attendance Pension Benefit. In addition, some state programs are specially designated for veterans.

**Long-term care insurance:** If your family member has long-term care insurance, it may cover some home care. Some policies permit family members to be paid, although they may exclude people who live in the same household. Ask your family member's insurance agent or contact the insurance company for an explanation of this benefit and its conditions.

**Caregiver contracts:** If none of these options apply to you, all is not lost, especially if the person you are caring for has some

savings or other assets. For example, a parent may be willing to work out a caregiver contract and pay a son or daughter for the care he or she provides. Consult an elder care lawyer to make sure that the contract meets tax requirements, deals with inheritances and is approved by all other interested parties, such as siblings). (To find elder law attorneys in your family member's area, go to [www.naela.org](http://www.naela.org).) Be mindful of the emotional pitfalls in this arrangement.



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**Other options:** If you are facing financial hardship because of a caregiving situation, here are some other options to consider:

- ▶ See whether your family member is eligible for programs that send an outside caregiver into the home so the responsibility doesn't fall only to you. Start with [Eldercare Locator](#) or [BenefitsCheckUp.org](#).
- ▶ Look into finding work you can do at home, or find a job that allows you the flexibility you need to be a caregiver.
- ▶ Hold a family meeting with siblings and others to discuss ways you can all share the financial burden.

Remember, your financial and emotional health should remain a top priority so you can continue to provide the kind of care your loved one needs.

(Adapted from Carol Levine, "[Can I Get Paid as a Caregiver?](#)" AARP.org, June 19, 2012.)

## 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.**