

Home Health Care

This information is meant to be a general introduction to this topic. The purpose is to provide a starting point for you to become more informed about important matters that may be affecting your life as a survivor and to provide ideas about steps you can take to learn more. This information is not intended nor should it be interpreted as providing professional legal and financial advice. You should consult a trained professional for more information.

Note: As with all LIVESTRONG™ documents, individuals living with cancer will be referred to as "survivors." Also in keeping with LIVESTRONG style, this document will talk directly to you, the survivor, even though the topic may not relate to your current needs or condition. The terms "family" and "loved ones" are used to mean all of the people that you care about and turn to for support, including relatives, spouses, partners and friends. The term "caregiver" is used to mean whoever is providing most of your day-to-day care, whether that person is a spouse, partner, child, sibling, relative, friend or privately hired person.

Home health care is a term that includes a wide range of medical, psychosocial, personal and rehabilitation services provided to individuals in their own homes. With medical advances, more and more care can safely be given at home instead of in a medical facility like a hospital, clinic or doctor's office. An important goal of home health care agencies is to enhance the well-being of everyone involved without taking over or replacing the role of your family and other caregivers.

Depending on need, home health care services can be provided on a temporary, short-term basis or on a long-term basis. For example, home health care can be used by people who are in the process of recovery, such as those recently discharged from the hospital. These services may also be appropriate for those who have a longer-term need for assistance, such as a newly disabled person or someone who is chronically or terminally ill.

Some cancer survivors face physical challenges during or after treatment that require ongoing assistance with health care. If this is something you or a loved one are facing, keep in mind that home health care may make it possible to continue to live at home without giving up the benefits of specialized health care. Many people find the home health care option preferable to an extended stay in a hospital or a move into an assisted living or nursing home facility.

This document provides an overview of the process of finding the home health care services that best meet your needs, including:

- When a survivor should consider home health care
- What kinds of home health care services are available
- What care providers are associated with home health care
- When a survivor should talk with a doctor about home health care

- How a survivor can get home health care services
- How a survivor can pay for home health care
- What to do if you have concerns about the home health care services provided
- How a survivor can find and select private home health care workers

When should a survivor consider home health care?

Home health care is usually considered when you cannot live comfortably and safely without additional support services. This type of care may be suggested by a doctor or other member of a health care team. In addition to the emotional comfort that the home environment may provide, home health care is usually less expensive than care provided in a medical facility. Access to hospitals or other health care facilities remains available as needed.

If there comes a time when these services are needed, be sure to research and compare a number of licensed home health care agencies. You can also consider the possibility of hiring your own caregivers. There are major differences in how home health care agencies and individual caregivers operate and you may find that one method meets your needs better than the other.

What kinds of home health care services are available?

Home health care falls into two broad length-of-care categories:

1. **Short-term (or acute) care:** Provides assistance following an illness or injury. The goal of short-term care is to provide the necessary services to help you get better, regain your ability to function and care for yourself and become as independent as possible.
2. **Long-term care:** Provides care for people who are chronically ill or more seriously or permanently disabled. The goal of long-term care is to help you maintain your highest level of function or health, and help you learn to adjust to and manage the changes resulting from your illness or disability.

Within these two categories there are different levels of care:

Custodial care (non-skilled care) is care that helps with activities of daily living like dressing, bathing and toileting. This type of care is often not covered by government-sponsored programs like Medicare.

Skilled care is a level of care that requires special training and skills and must be provided by a licensed professional and prescribed by a doctor. Government-sponsored programs may pay for medically necessary skilled care.

The following are types of skilled care services:

- **Intermediate care services** include nursing and rehabilitative care that is provided at a level between intensive and basic care. These services are ordered by a doctor and supervised by skilled medical personnel.

- **Intermittent services** are usually defined as skilled health care services that are needed or provided fewer than seven days each week or less than eight hours per day over a period of 21 days.

What care providers are associated with home health care?

Certified home health care agencies employ a variety of care providers to deliver services. In addition to nursing care and home health aide services, agencies can provide or arrange for specialized services with social workers or physical, occupational or speech therapists. Home health care agencies can also assist with arrangements for medical supplies and equipment or nutrition programs, such as home-delivered meals.

With a doctor's order, the following caregivers may be arranged through home health care agencies:

1. Licensed care providers

- **Registered nurses (RNs) and licensed practical nurses (LPNs)** can give medication, change bandages, administer treatments, monitor pain or other symptoms and check vital signs (temperature, blood pressure, heart rate, breathing rate).
- **Occupational Therapists (OTs), Registered Physical Therapists (RPTs), Nutritionists and Social Workers (MSWs)** can provide home health care services prescribed by a doctor in their professional area of specialty.

2. Attendant caregivers

- **Certified nursing assistants (CNAs)** must complete a state-approved training program and competency test. CNAs perform routine tasks under the supervision of licensed nursing and medical staff, such as wound and skin care, checking vital signs, helping with transfers (moving from one place to another), assisting clients with ambulation (walking), prescribed exercises and other care procedures. CNAs may also provide assistance with activities of daily living (ADLs). ADLs are those activities that are necessary for people to be able to live independently, including bathing, toileting, eating and moving around the home.
- **Home health aides** may assist with personal services and ADLs, such as bathing, toileting, eating, ambulation and transfers.
- **Personal care attendants (PCAs), homemakers or companions** can only assist with cleaning, cooking, laundry and other household chores. They may also help with shopping or accompany clients to appointments or other errands.

3. Respite caregivers

Respite care services offer other caregivers a temporary break from the day-to-day demands of caring for another person on a full-time basis. Respite care is usually needed by the primary caregiver of someone who is severely or chronically disabled. Services may include housekeeping, home health assistance, nursing and child care.

4. Hospice caregivers

Hospice is a specialized service that provides a compassionate, supportive network of professionals and volunteers to help manage the many physical, practical and spiritual challenges that often occur at the end of life.

Hospice services can include skilled and unskilled nursing care, pain management, and assistance with getting personal and legal affairs in order, as well as many options for emotional support. Hospice workers include nurses, social workers, home health aides, volunteers, therapists and pastoral counselors. Services may be provided at home or in a hospital or nursing home.

The following hospice documents can be found in the list of Practical Topics:

- What Hospice Care Means for Survivors
- What Hospice Care Means for Caregivers

When should a survivor talk with a doctor about home health care?

If you think you may have a need for home-based health care services, talk about your needs with your doctor. The doctor must prescribe or order skilled home health care services in order for insurance to pay. Tell your doctor about any problems you are having with daily activities and ask the doctor about what types of health care services might be helpful to you at home.

Be certain to include the following in your discussion with your doctor:

- Concerns about being home alone
- How often a caregiver might be required
- Types of assistance that will be needed, such as cooking, cleaning or help with other ADLs
- Barriers to getting around your home, such as climbing stairs or physical challenges such as walking the distance to the bathroom, kitchen or bedroom

Before your meeting with the doctor to discuss these matters, write down your concerns and questions. This discussion will help define how much and what type of home health care services may be needed, such as skilled or intermittent care.

How can a survivor get home health care services?

There are two main ways that home health care services are obtained: licensed home health care agencies and workers that you hire on your own ("private pay").

Home health care agencies coordinate and supervise the provision of skilled services (such as wound care, injections and other medical care) in your home according to your needs and as ordered by your doctor. Home health care agencies are licensed. If the agency has also met federal and/or state minimum requirements for patient care, it is Medicare-certified and has qualified for Medicare and/or Medicaid payments for home health services.

If you have a doctor's order or prescription and work with a licensed and certified agency, costs for services may be covered through an employer-sponsored, private or government-sponsored insurance plan. Frequently, only part-time and/or temporary home health care services are covered. Talk with your insurance provider about your specific plan, what is covered and what is required to qualify for coverage.

Your insurance company may have a relationship with certain home health care agencies and direct you to a specific service provider. Generally, you have the right to choose the home health care provider that you want, although members of certain insurance plans may have their choices limited to the agencies that are listed in the policy.

If home health care is needed following a hospitalization, a hospital social worker will usually initiate contact with a home health care agency and coordinate services with the doctor, as well as with you and your family. Local and national cancer organizations and agencies for the aging may also be able to suggest home health care providers. Keep in mind that a home health agency has the right to refuse to accept any individual patient if the agency is not able to meet the patient's needs.

Private home health care workers are individuals hired directly by you or your family, such as through a friend, a classified ad or a similar "help wanted" posting. These caregivers typically provide companionship and help with ADLs, such as housecleaning and meal preparation.

If you plan to pay for home health care services on your own, such as by hiring a personal care attendant, this can be arranged directly and does not require the orders of a doctor. However, licensed nursing services that are provided by a RN or LPN do require a doctor's order.

Researching home health care agencies

Begin your research by asking health care team members (such as your doctor, nurse or therapist) to help you with recommendations and contact information for home health care agencies. A hospital social worker, cancer organization or your Health and Human Services office may also be able to direct you to local resources that are available.

The following are steps you can take to research home health care providers:

1. Think through what your medical or home health care needs are now, as well as what they are likely to be in the next few months.
2. Once you identify some home health care agencies that appear to be able to meet your needs, check each agency's credentials. Organizations such as the Joint Commission on Accreditation of Health Care Organization (JCAHCO) can provide information about agencies.
3. Check the home health care agency's reputation locally by speaking with your doctor, social worker or local cancer organization. You can also learn whether the agency is experienced in treating people with cancer.
4. Decide whether the level of care that the agency provides will meet your needs. The home health care agency should be able to provide you with an individualized plan of care that lists:
 - The services the agency will provide
 - The names of the people who will perform each service
 - The qualifications and training of those who will be performing each job
 - How often agency personnel will visit
5. Find out if the services of the home health care agency are covered by your insurance. If so, how much of the cost will you have to pay? If the services are not covered by your insurance, find out what the cost will be to you and whether the cost can be negotiated to be less.

You will have a say about which home health care agency you use, but your choices may be limited by agency availability or a factor such as Medicare rules. Some hospitals have their own home health care agency, but this does not mean you have to choose the hospital's agency.

As you research home health care agencies, note the following information about each agency:

- The name, address and phone number of the agency
- Whether the agency has Medicare certification
- Type of ownership, such as for-profit, nonprofit or government

- Information from state or federal surveys, such as how well the home health care agencies provide care for their patients
- Services offered by the agency, such as nursing care, physical therapy, occupational therapy, speech-language pathology, medical/social services and home health aide

Comparing the quality of care provided by home health care agencies

Home health care agencies are certified to make certain they meet federal health and safety requirements. You can get information about home health agencies and the results of their quality measures from a Medicare agency. In some cases, a local ombudsman, who can be contacted through your local agency on aging, may have information on quality care measures of home health agencies in your area.

Quality care means doing the right thing, at the right time and in the right way to obtain the best possible results for the patient. Quality care measures give you information about how well home health agencies provide care for patients. The quality care measures include information about the physical and mental health of patients, and whether the patient's ability to perform basic daily activities improved while under the program's care. Patients are monitored for quality measures in areas such as:

- Improvement in mobility (ability to move around the home)
- Patient medical emergencies
- Improvement in mental health
- Ability to perform ADLs, such as bathing, dressing, eating, using the bathroom

The home health care agency staff is responsible for developing a care plan that is written specific to your needs. You and your loved ones have a right to participate in planning your care and discussing your treatment options. Your doctor is kept informed by agency staff on how you are doing.

Care plans are developed for individuals as part of the case management process. These written plans outline all of the services and caregiving arrangements that are needed to help the individual achieve the best quality of life possible. A multi-disciplinary team (that may include family members, nurses, dieticians, doctors, therapists, activities and social services professionals) defines timeframes and specific care services to be provided.

Your care plan is periodically reviewed by the home care team and adjustments are made to the care plan as needed to reflect your current needs. Home health care staff cannot make changes to the care plan your doctor has ordered without the doctor's knowledge and permission.

Home health care agencies are responsible for:

- Screening and training the health care workers
- Providing workers who meet licensing requirements and qualifications
- Providing workers compensation insurance if this is required in your state
- Supervising its health care workers
- Providing an insurance bond at an extra cost to repay you in case of theft

For assistance finding a home health care agency, ask your doctor, hospital discharge planner or social worker what they know about various service providers in your area. Friends and family may also have information to share about their home health care experiences. Referral services may also be provided by a cancer organization or local community service agencies.

How can a survivor pay for home health care?

Home health care services can be costly. Some home-based services may be partially covered by private medical and disability insurance policies. However, home health care on a long-term basis may have to be financed through personal funds and/or state and federal medical assistance programs, such as Medicaid and Medicare.

Medicaid is a government assistance program for people who meet certain low income requirements. Medicaid is jointly funded by the federal and state governments and operates under national and individual state guidelines. Eligibility for Medicaid varies from state to state. Some states have "medically needy" options to cover the cost of medical care for persons who would qualify for Medicaid on the basis of the services they require, but have too much income to qualify for the program and too little to pay for the needed medical services.

Medicare is a national health insurance program that pays for acute medical care services for people age 65 or older or those who have qualified for government disability benefits.

Check your insurance coverage to find out if your home health care needs will be paid for by insurance and for how long. If your policy or government program does not normally cover those needs, ask your doctor or a home health care company to negotiate for you with the insurance carrier. If it can be shown that it is less expensive to deliver the needed services to you at home rather than in a hospital, then the care might be approved.

In most cases you need to meet all of the following conditions to be eligible for insurance or Medicare-covered home health care benefits:

1. Your doctor must determine that you need medical care, and write a prescription referring you to home health care services.
2. You must need at least one of the following care services: intermittent skilled nursing care or physical therapy, speech-language therapy, or ongoing occupational therapy.

3. You may need to choose a home health agency that is certified or approved by the insurance company or assistance program. For example, the agency may need to be Medicare-certified.

4. You must meet certain requirements such as not being able to leave home unassisted or being confined to home by illness. Leaving home for medical treatment, adult day services or short, infrequent trips is allowed.

Rates for home health care are based on the level of service, individual agency rates, and the rates typically charged in the area in which the services are provided. Contact several agencies to compare services offered and rates charged before deciding to contract for services.

There may be limits on the number of hours per day and days per week that you can get skilled nursing or home health aide services. Contact your insurance company to find out specifically what home health care services are covered. If you have Medicare or Medicaid, the Centers for Medicare and Medicaid Services can provide you with information.

If you are eligible for home health care, services such as the following are likely to be covered:

1. Skilled nursing that is performed by a registered nurse or a licensed practical nurse on a part-time or intermittent basis
2. Home health aide services on a part-time or intermittent basis
3. Physical therapy, speech-language therapy and occupational therapy for as long as the doctor says you need it
4. Medical social work services to help you with social and emotional concerns related to your illness; these services may include counseling or help in finding community resources
5. Certain medical supplies, but not prescription drugs
6. Medical equipment such as a hospital bed, wheelchair or walker

On the other hand, there may not be insurance coverage for things such as:

- 24-hour-a-day care at home
- Prescription drugs
- Meals delivered to your home
- Homemaker services such as shopping, cleaning and laundry
- Personal care services given by home health aides such as bathing, dressing and using the bathroom when this is the only care you need

When there is a need for medical equipment in your home, your doctor should write a prescription or order for the equipment that is needed. Your discharge planner or social worker can then discuss your needs with the insurance company on your behalf to find

out in advance if insurance will pay for the purchase or rental of the equipment ordered by the doctor.

If your insurance company will not automatically pay for needed home health care equipment, try taking the following steps:

1. Compare the costs of obtaining the treatment at home to the cost of getting the care at a medical facility.

If it will cost less to provide the care in your home, speak with a supervisor at the insurance company and present the costs of each option. It is possible that the insurance company may agree to pay for the equipment.

2. Check to see if it is possible to borrow the equipment.

An area agency on aging or another community service group may be able to assist you with finding a supplier from which you can borrow the equipment.

3. Compare costs to see if it is cheaper for you to rent the equipment or buy it.

When comparing the costs of renting or purchasing medical equipment, include the cost of servicing the equipment. If you rent, equipment maintenance may be free.

What if you have concerns about services provided through a home health care agency?

If you have concerns about the home health care work you are receiving, start by speaking directly with the person providing the care to let him or her know your concerns. If that does not improve the situation, speak with the home health care provider's supervisor or the agency owner. If there is still no improvement in the work, ask for a new health care worker. Be sure to let your doctor know of any unresolved concerns or problems with the agency.

If you find that you do not feel comfortable with the home health care you receive, you can change home health care providers. A close friend or family member can speak on your behalf if you do not want to personally deal with the problem. Keep in mind that because of federal laws about health privacy, the home health care agency will need written permission to speak with someone other than you about your care.

If a problem with the health care provider cannot be resolved to your satisfaction, you will likely want to change agencies and/or health care workers. The following are basic guidelines for changing your home health care provider:

1. You may choose to end your relationship with one home health care agency and choose another at any time.

2. If you need to change agencies, contact your doctor to get a referral to a new home health care agency. You must notify both the agency you are leaving and the new agency of the date that the change will take effect.
3. Before you make any arrangements to change home health care agencies, be certain that the change is pre-approved by your insurance provider(s).
4. Keep in mind that you can only get care from one home health agency at a time.

Your day-to-day home health care should be supervised by you or someone you trust as well as by your medical team. If necessary, changes can be requested so that the care you receive meets your needs. As a patient of a home health agency, you have rights. A Medicare-approved facility must provide you with a written copy of your rights.

The rights for a home health care patient include:

- The right to choose your home health agency
- The right to have your property treated with respect
- The right to have your family or guardian act on your behalf
- The right to file a complaint about your treatment or care if it is not provided appropriately or if the staff shows disrespect for you or your property
- The right to be given a copy of your plan of care that documents the types and frequency of services
- The right to know about the staff that the home health agency will provide

Keeping notes on the quality of home health care you receive is helpful. For example, write down the names of people providing the care, the dates they worked, how long they stayed and the quality of their services. Keep these notes in a secure place.

Most home health care agencies and their staff are honest and use accurate billing information. Unfortunately, fraud (cheating), waste or abuse may occur. Watch for possible signs, such as:

1. Home health visits that your doctor ordered, but you never received
2. Visits by home health staff that are not needed
3. Bills for services and equipment you never got
4. Forging of your signature or your doctor's signature
5. Pressure to accept items and services that you do not need

The best way to protect yourself is to know what your insurance covers and what your care plan is. If you do not understand something in your care plan, ask questions. You have a right to participate in the development of your care plan. If you suspect that something is wrong, ask your doctor, your hospital social worker, or trusted family or friends for help.

How can a survivor find and select private home health care workers?

In some cases it may be less expensive to hire a caregiver directly rather than through a home health care agency. For example, if you are not looking for skilled medical care, but need someone to act as a companion or personal aide, hiring a home health care worker on your own may be less costly. However, locating and hiring a home health care worker may also be much more complicated and time-consuming than going through an agency.

If you do decide to find your own home health care worker, be aware that you will be required to take responsibility for certain things. Carefully consider these responsibilities. For example:

- You may have to withhold taxes as an employer for the worker.
- You need to have a written contract with the home health care worker, particularly if he or she is going to live in your home. If the caregiver is going to live with you, it must be clear in the contract that their right to stay in your home continues only as long as that person works for you.
- You need to be certain that the home health care worker is covered by personal liability or worker's compensation insurance so that you are covered in case there is a liability claim, such as an injury in your home.
- You need to do background check to make certain that the health care worker you hire has no record of criminal activity or abuse. Some states have registries (many are available online) for personal care attendants and home health aides that make it easier for you to do the background check.
- You need to have a back-up plan for care in case the worker becomes ill or unavailable at short notice.

After a potential health care provider has been identified, you will need to interview and select the home health care worker(s). Start by defining what help is needed and preparing a job description that lists the services that you want the home health care worker to provide. Design the job description as a contract that will be signed by both you and the home health care provider. Include the full names of you and the health care worker, a list of duties and responsibilities of the worker, wages and benefits that will be paid, work and vacation schedules, and any other information that you think is important.

Interview potential health care workers in your home where there is an opportunity for the caregiver to become acquainted with you and any family members. The interview and selection process should be a time for an open and honest discussion between you and the health care provider. This is the time to ask questions and to cover all topics that are of concern to you. Ask the caregiver how he or she would respond in specific situations and

request that they provide examples from past experience that show how they solve problems.

When selecting a private home health care worker:

1. Find out if the home health care worker listens and communicates well.
2. Find out if the caregiver can perform all of the tasks defined in the job description you developed for the position.
3. Make certain that you and the home health care worker feel comfortable with one another and in your home.
4. Discuss the best ways to communicate with you and any family members.
5. Familiarize the home health care worker with special medical equipment that will be used.
6. Discuss any special needs and procedures that may be necessary in an emergency.
7. Share specific information about your disability.
8. Discuss any factors in the home, such as pets, that may be an issue for the home health care worker.

Before the selecting a home health care provider, be certain he or she is:

- in good overall health
- physically able to perform the duties of the job
- cleared by professional references and a background check with no history of abuse or neglect
- able to provide proof of a valid driver's license or state identification card and Social Security card (for W-2 or W-3 form and I-9 form)

Make it clear to the home health care provider that you will not tolerate abuse, neglect, chronic tardiness, absenteeism or failure to perform assigned duties. Discussing a set of rules and job requirements is important before signing an employment agreement.

Other ways to find home health care providers:

Home health care registries are independent contractors that provide services at prices that are usually lower than home health care agencies. They operate somewhat like an employment agency in that they screen, interview and do reference checks on home health care workers that are referred. Be sure that any agency you select can provide the caregivers you need.

Some states and counties offer home health care services to people who are disabled or to family caregivers. An application for assistance is reviewed and evaluated by need. If you qualify for program services, home health care aides may be provided.

Finally, some families elect to set up formal caregiver contracts (also called personal service or personal-care agreements) to hire a family member to provide care services. These legal contracts name the specific services to be performed, the rate of pay to be provided the caregiver and when it will be paid, such as in one lump sum or in regular

payments. Talk with an attorney who specializes in this area to receive guidance if you decide to set up such a contract. There is also information on caregiving contracts and related matters available online, such as through the National Academy of Elder Law Attorneys.

In some cases, it may be possible to use a long-term care insurance policy to pay family members who provide the caregiving services. Some government programs (such as a state Medicaid "Cash and Counseling" program) provide funding to pay family members for "consumer-directed care." Local agencies on aging or departments of social services may be able to provide more information on government funding.

The ultimate goal of home health care is to make it possible to remain in your home in a safe and comfortable environment while enjoying a better quality of life. Although you may go through a period of adjustment to a new care routine, it is important that you feel safe and satisfied and that you are receiving a high standard of care.

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