

Living with ALS at Home

Home health care resources for people with ALS



BAYADA Home Health Aide Rebecca Miller discusses nutrition with client with ALS Royce C.



Table of Contents

- Forward 2
- What is Home Health Care? 3
- Who Provides Home Health Care? 5
- When to Start Home Health Care 5
- Indications that Home Health Care is Needed 6
- Caring for the Caregiver 7
- How to Pay for Home Health Care 8
 - Medicare and Medicaid 8
 - Managed Medicaid, private insurance, long-term care insurance 9
 - Private pay, charitable organizations, Veterans Administration 10
- Benefits of Home Health Care 11
- Why Choose Professional Home Health Care Services? 11
- Finding a Provider that's Right for You 12
- What is the Process of Obtaining Home Health Care? 13
- Sharing Your Home with Your Care Team 14
- How Your Care Team Prepares to Share Your Home 15
- About The ALS Association 16
- Glossary of Health Care Terms 17

Foreward

Helping those with ALS live at home with comfort, independence, and dignity

The ALS Association and BAYADA Home Health Care are proud partners in raising awareness about ALS and enhancing the lives of those living with the disease. Our shared mission and combined resources allow us to do more together, helping people with ALS and their families experience a better quality of life.

We understand the difficulties of daily living for people with ALS and the complexity of caring for a loved one living with the disease. We also know how important it is to have access to information and resources that both people with ALS and their families need to navigate their way as the disease progresses. That's why we are pleased to provide this booklet as a basic guide to understanding what home health care resources are available and how they can help.

From assistance with activities of daily living to complex nursing care, home health care services can give you and your loved ones the support and peace of mind you need and deserve. In addition to learning about how medical and non-medical services can help, you'll also find information about when to start care, guidance on how to pay, how to find a provider that's right for you, and so much more.

The mission of The ALS Association is to lead the fight to treat and cure ALS through global research and nationwide advocacy, while also empowering people with ALS and their families to live fuller lives by providing them with compassionate care and support. Together with BAYADA, we are committed and truly honored to play a significant role in helping those with ALS live at home with comfort, independence, and dignity until there is more effective treatments and a cure.

What is Home Health Care?



BAYADA Clinical Manager Karen Logan, RN, answers questions from client Dr. Frances S.

Home health care plays an important role in the health care system. People with injury, illness, or disability are now able to receive care at home that was once only provided in hospitals.

The most commonly provided home health care services for people with ALS are nursing and assistive care (personal care based on your eligibility); however, other services such as therapy and hospice are available as well.

Nursing care services are provided by registered nurses and licensed practical nurses who specialize in home health care. They are often highly experienced and knowledgeable professionals who can help you with all your care needs, ranging from management of ALS symptoms to tracheostomy and ventilator care. Care is typically provided in shifts (two hours or more) on an ongoing basis.

Home health care nurses usually provide:

- Management of a tracheostomy, using a ventilator, as well as suctioning care
- Nutrition via a feeding tube
- Assistance with communication devices such as a symbol and picture board or iPads
- Management of bowel programs
- Assistance with mobility while managing energy reserves
- Administration of medications and treatments, including IV
- Education about the disease

Assistive (personal) care is non-medical assistance with activities of daily living when the disease has made it difficult to manage everyday tasks on your own. This type of care can be provided by home health aides, certified nursing assistants, homemakers, and companions. Many people with ALS benefit from assistive care throughout their diagnosis as their disease progresses. Care is typically provided in shifts (two hours or more) on an ongoing basis. Breadth of services depends on a state's scope of services.

Care services typically include help with:

- Communication devices, such as a symbol and picture board or iPads
- Dressing and grooming with the use of adaptive equipment, such as button hooks or zipper pulls
- Bathing and toileting
- Safe walking, repositioning, and transferring
- Meal preparation, eating, and nutrition

- Light housekeeping, such as vacuuming, dusting, washing and folding laundry, and trash removal
- Shopping for groceries and other minor errands
- Medication and appointment reminders (varies by state and practice)

Therapeutic care includes physical therapy, occupational therapy, speech language pathology, and respiratory therapy, all of which can help you manage your condition safely at home, increasing independence and comfort.

Physical Therapists can provide:

- Prescriptions for ambulatory devices that include, but are not limited to, the use of walkers, wheelchairs, and power wheelchairs depending on the point in progression of the disease
- Range-of-motion and stretching exercises to prevent and manage pain and improve function
- Assistance with transfers using a Hoyer Lift or other equipment

Occupational Therapists can provide:

- Assistance with activities of daily life by teaching new strategies for completing tasks, recommending adaptive devices, and providing training, evaluating the home for potential modifications
- Therapeutic interventions to help maximize independence

Speech Language Pathologists can provide:

- Assistance with communication using augmentative communication devices
- Assessment and treatment of swallowing disorders
- Recommendations to reduce the risk of aspiration

Hospice can provide a loving, respectful, and peaceful end to an otherwise difficult experience with ALS. Services include medical care and symptom and pain management as well as emotional and spiritual support to both you and your loved ones. A hospice care team usually includes nurses, physicians, therapists, social workers, and home health aides who specialize in comfort and end-of-life care.

Hospice services include:

- Nursing and physician care
- Social work and counseling
- Spiritual care based on values
- Bereavement support
- Respite care and companionship
- Therapies
- Palliative care

Hospice also provides medication and medical equipment and supplies related to the primary hospice diagnosis and related conditions.

Who Provides Home Health Care?

Home health care may be provided by either home health care agencies or by privately hired caregivers.

Privately hired nurses and personal care aides may provide the same type of services as home health agencies do; however, agencies are bound by licensure statutes and state and federal regulations that ensure competency of their care staff. That means that the nurses and aides hired through an agency have met specific hiring standards. In addition, home health care providers may be accredited by many different governing bodies such as Community Health Accreditation Partner (CHAP), certified by Centers for Medicare and Medicaid Services (CMS), and licensed by the state.

A reputable agency should use professional recruiting practices including verifying work history, credentials, and references, as well as performing thorough background checks. Conducting in-depth interviews, written testing, and hands-on skills assessments helps ensure that the caregivers they hire have the appropriate skills and background to meet their responsibilities. All caregivers should be fully insured before they visit their first client.

Hiring a caregiver privately puts the responsibility on your family to determine if the person hired is qualified and experienced enough to care for you. It can be difficult to verify the credentials and skills of a privately hired caregiver.

When to Start Home Health Care



BAYADA Home Health Aide Rebecca Miller discusses support for Natalie C. and her husband with ALS.

It's not uncommon for family caregivers to wait to learn about care options for their loved ones until they "really need" the help. Looking back, however, they often realize that they needed help long before they finally asked for it.

Indications that Home Health Care is Needed

For People with ALS	YES	NO
Do you:		
Have difficulty accomplishing household tasks (laundry, cooking, dishwashing)?	<input type="checkbox"/>	<input type="checkbox"/>
Struggle with personal care tasks (bathing, dressing, grooming)?	<input type="checkbox"/>	<input type="checkbox"/>
Need assistance getting in and out of bed?	<input type="checkbox"/>	<input type="checkbox"/>
Worry about being safe when left alone?	<input type="checkbox"/>	<input type="checkbox"/>
Live far from family members or close friends who can help with care?	<input type="checkbox"/>	<input type="checkbox"/>
Need more advanced care than a family member can provide?	<input type="checkbox"/>	<input type="checkbox"/>
Have difficulty swallowing?	<input type="checkbox"/>	<input type="checkbox"/>
Need help with medication management?	<input type="checkbox"/>	<input type="checkbox"/>
Experience breathing problems?	<input type="checkbox"/>	<input type="checkbox"/>
Fall on a frequent basis?	<input type="checkbox"/>	<input type="checkbox"/>
Have mobility issues (need assistance from a walker or wheelchair)?	<input type="checkbox"/>	<input type="checkbox"/>
Require assistance with a ventilator?	<input type="checkbox"/>	<input type="checkbox"/>
Experience frequent hospital admissions?	<input type="checkbox"/>	<input type="checkbox"/>
Need assistance 24 hours a day?	<input type="checkbox"/>	<input type="checkbox"/>

For Caregivers	YES	NO
Are you:		
Fearful of leaving your loved one alone?	<input type="checkbox"/>	<input type="checkbox"/>
Finding that your loved one's care is becoming exceedingly demanding on your time, emotions, and physical abilities?	<input type="checkbox"/>	<input type="checkbox"/>
Unable to have respite time for yourself?	<input type="checkbox"/>	<input type="checkbox"/>
Unable to provide the advanced care that your loved one requires?	<input type="checkbox"/>	<input type="checkbox"/>
Unable to take care of household tasks due to caring for your loved one?	<input type="checkbox"/>	<input type="checkbox"/>
Missing out on your own social and personal activities because of caring for your loved one?	<input type="checkbox"/>	<input type="checkbox"/>
Unable to assist your loved one with personal tasks (bathing, dressing, grooming) on a consistent basis?	<input type="checkbox"/>	<input type="checkbox"/>

Caring for the Caregiver

When your loved one receives a diagnosis such as ALS, the focus is often solely on the patient. However, it is important for the family caregiver to take care of themselves, so that they can provide the best care for their loved ones as well.

Here are some helpful questions to consider as the family caregiver to ensure your needs are taken care of, too:



Michael Macekura, and his wife, Diane spend time on activities they both enjoy.

- What do you do to take care of yourself?
- How often do you get a full night's sleep?
- Are you in good health?
- Do you exercise regularly?
- What are your favorite hobbies?
- Are you delaying fulfillment of personal goals?
- Are you able to work?
- Who do you speak to when you need support?

How to Pay for Home Health Care

Home health care providers that offer a broad range of services and accept a wide range of payer sources are able to care for people with ALS throughout the progression of their disease. Many of these home health care providers have specialists who can help clients and families navigate their eligibility for the various payor sources.

Medicare

Medicare is a form of health insurance provided by the federal government for people over 65 or those under 65 with disabilities. For people with ALS, Medicare covers assessments for speech language pathology, and physical, occupational, and respiratory therapies. It also covers durable medical equipment (DME), as recommended by a physical therapist. Medicare covers consultations with physical therapists to teach family caregivers and/or personal care assistants (home health aides or certified nursing assistants) how to help with range-of-motion exercises and how to use the DMEs. Hospice care is also covered under Medicare.

There is no 24-month waiting period for people with ALS to receive Medicare benefits. People with ALS, who are deemed to be homebound, will receive Medicare benefits as soon as they receive social security disability benefits. However, Medicare only covers intermittent, short-term care needs. People with ALS typically need long-term, skilled, and personal care that is not covered by Medicare.

Visit [medicare.gov](https://www.medicare.gov) for more information.

Medicaid

Medicaid is another type of government insurance that covers medical costs for those with low incomes, or those with higher incomes, but whose medical costs are over a certain percentage of their income. Medicaid is a joint federal and state program and eligibility requirements vary from state to state. The federal government does not require state Medicaid plans to cover home health care services; however, states may choose to offer home health care services as part of their state plans.

Visit [medicaid.gov](https://www.medicaid.gov) for more information.

Managed Medicaid

Managed Medicaid is an arrangement between an individual state and managed care organizations. Each managed care organization receives a capitated rate from the state. Programs and services vary from state to state. The plans operate similarly to a private health plan. If you are eligible for Medicaid, you will be assigned a case manager who can help navigate the benefits that may be covered, which vary by state.

Visit [medicaid.gov](https://www.medicaid.gov) for more information.

Private insurance

Private health insurance is provided through an employer or spouse's employer from a private health insurance company or managed care organization. Private insurance plans may also be purchased individually. Home health care may or may not be covered by private insurance as this varies from policy to policy. If you had private insurance prior to your diagnosis, you should check your policy for an ALS exclusion. If there is no ALS exclusion, check the policy to see if it covers private duty nursing and home health benefits. Most insurance companies that cover home health care benefits without a skilled need (personal care) are covered for short-term, intermittent periods.

If you had been denied coverage from private insurance, we suggest that you file an appeal as long as the insurance plan covers private duty nursing or home health benefits.

Long-term care insurance

Long-term care insurance covers in-home services, such as skilled nursing, therapeutic care, and personal care. If ALS is covered under the long-term care insurance plan, home health care services will be covered. Most likely, if you do not already have long-term care insurance, you will not be able to purchase it after your diagnosis.

Private pay

If the financial resources are available, services may be paid for privately. All rates should be negotiated.

Many home health care companies work with you if you are paying privately. It is important to negotiate rates and payment plans especially when paying privately for services. You should develop a long-term financial plan when considering home health care. Some clients with ALS use the following options to help pay for services: savings, reverse mortgages, home equity lines, life insurance policy conversions, and home care loans.

Charitable organizations

There are many organizations that can help pay for home health care for those with ALS. Local foundations and other associations may be set up to raise funds to pay for patient care. The ALS Association chapters provide a variety of programs and services.

Veterans Administration

ALS is considered a service-connected disease. The Veterans Administration (VA) will assume that any veteran diagnosed with ALS who served for a minimum of 90 continuous days on active duty was diagnosed because of, or aggravated by, their service in the military, regardless of when or where they served.

Military veterans with ALS who were previously denied benefits should contact their local chapter of The ALS Association or other veterans' service organizations to seek guidance about reopening their claim.

VA health benefits may include prescriptions, medical supplies, home improvement and structural alterations, as well as home health care coverage. To apply for benefits, you may contact your local chapter of The ALS Association or other veterans' service organizations to seek guidance and assistance on the application process.

Benefits of Home Health Care



Person with ALS Royce C. (seated), his wife Natalie, daughter Lillian, BAYADA Home Health Aides Rebecca Miller and Pamela Strong, and Director Nick Vollmer

Home health care provides many benefits to both people living with ALS and their loved ones. Helping people with ALS remain safe in the comfort of their own homes, surrounded by friends and family is one of the most important aspects of home health care. Here are some additional ways home health care can benefit you and your family:

- Convenient care in one place
- Daily connections with loved ones
- Family collaboration (family caregivers are part of care team)
- One-to-one care (individualized care and attention)
- Respite for the family caregiver
- Clinical oversight and assessment
- Support and education for family caregivers
- Ease of transition when a higher level of care is needed

Why choose professional home health care services?

Professional home health care offers peace of mind and reassurance that the person in your home, caring for you, is:

- Qualified and experienced
- Supervised by a registered nurse
- Accountable to the authority and regulations of the agency and governing bodies
- Trained and receives ongoing education

Agencies protect you from:

- Workers' compensation claims
- Tax liabilities
- Hiring caregivers who cannot work in the US legally
- Loss and damages resulting from caregiver theft or negligence

Agencies can offer:

- 24/7 access and support
- Direct billing to payor sources
- Ongoing clinical supervision for all levels of care
- Continued coverage even when primary caregiver is unavailable
- Health insurance confirmation and navigation of benefits

Finding a Provider that's Right for You

Once you determine that home health care is needed, finding the right provider is an important next step. When researching providers, here are some key points to consider:

Services:	Provider 1	Provider 2
Both assistive care (hourly and live-in) and nursing services based on clients' needs	<input type="checkbox"/>	<input type="checkbox"/>
Free, confidential assessment by a registered nurse (RN)	<input type="checkbox"/>	<input type="checkbox"/>
Assessment-based care plans written by RNs in collaboration with client and family	<input type="checkbox"/>	<input type="checkbox"/>
Regular RN supervision and support of employees in clients' homes	<input type="checkbox"/>	<input type="checkbox"/>
Therapy services available as needs change in the future	<input type="checkbox"/>	<input type="checkbox"/>
Ability to offer services throughout the continuum of care (therapeutic, skilled, etc.)	<input type="checkbox"/>	<input type="checkbox"/>
Guarantees:		
No contracts	<input type="checkbox"/>	<input type="checkbox"/>
No cancellation fees	<input type="checkbox"/>	<input type="checkbox"/>
Caregivers are employees—not contractors—of the provider	<input type="checkbox"/>	<input type="checkbox"/>
Employees fully insured for liability and workers' compensation	<input type="checkbox"/>	<input type="checkbox"/>
Credentials:		
Community Health Accreditation Partner (CHAP) accredited	<input type="checkbox"/>	<input type="checkbox"/>
State licensed	<input type="checkbox"/>	<input type="checkbox"/>
Medicare-certified and Medicaid-approved	<input type="checkbox"/>	<input type="checkbox"/>
Hiring and training standards:		
Personal interviews	<input type="checkbox"/>	<input type="checkbox"/>
Reference checks	<input type="checkbox"/>	<input type="checkbox"/>
Criminal background checks	<input type="checkbox"/>	<input type="checkbox"/>
Competency evaluation and testing	<input type="checkbox"/>	<input type="checkbox"/>
Ongoing education and training (including dementia and rehabilitation)	<input type="checkbox"/>	<input type="checkbox"/>
Documentation:		
Clients' rights and responsibilities	<input type="checkbox"/>	<input type="checkbox"/>
Privacy notices	<input type="checkbox"/>	<input type="checkbox"/>
Customer service:		
Bills client's insurance directly	<input type="checkbox"/>	<input type="checkbox"/>
On call 24 hours a day, 7 days a week	<input type="checkbox"/>	<input type="checkbox"/>
Ongoing client satisfaction surveys	<input type="checkbox"/>	<input type="checkbox"/>

What is the Process for Obtaining Home Health Care?

Some home health care agencies will help you determine your eligibility for services. They will contact your insurer on your behalf or explore benefit coverage through other payor sources such as Medicaid or the Veterans Administration. However, for those agencies that do not provide this assistance, it's wise to check into your coverage before getting too deeply into discussions about specific services. Eligibility and benefits can vary greatly from one situation to the next, so it's important to understand your options.

Once you have found an agency that appears to be a good fit and accepts any insurance benefits you may have, you can move forward with arranging services. Each agency may vary in terms of how they deliver care based on their own internal policies as well as criteria set by their accrediting body, such as Community Health Accreditation Partner (CHAP). CHAP is an independent, nonprofit, accrediting body with the regulatory authority to audit agencies to determine if they meet the Medicare Conditions of Participation and the CMS Quality Standards.

Most larger, full-service home health care agencies will provide you with a dedicated staff for both clinical and administrative support needs. They may include a:



BAYADA Clinical Manager Pat Pagano, RN, ensures that her clients receive exceptional care.

- Client services manager (or office support manager) who is responsible for matching a caregiver(s) who best fits your specific needs, personality, and wishes, as well as those of your family. The client services manager should manage the care schedule and ensure you receive all the services to which you are entitled, based on your needs and what has been authorized by the payor source.
- Clinical manager who oversees your care and supervises the aides and nurses providing the day-to-day care.

Sharing Your Home with Your Care Team

Preparing to welcome your caregiving team into your home can be a daunting process. Many people with ALS fear loss of privacy and have anxieties regarding disruption of their home and family routines. It is important to maintain as much normalcy as possible. When preparing to share your home with your care team, consider the following to help ease the transition:



Michael Macekura, with his wife Diane, and his BAYADA Nurse Carol Coghill

- Ask yourself, “How can my care team respect my privacy?” This may help you determine boundaries for your care team.
- Maintain private areas of your home for yourself and your family if possible. Establishing boundaries or “off limit” places may be helpful to maintain your family’s normal routine and privacy.
- Set up a place for your care team to write their required home health care documentation notes, hang their coat, and store their food.
- Share details of your normal routine with your care providers so that they have an understanding and can adapt.
- Share any cultural or religious considerations with your care team that are important to you and your family, such as preferred language or food restrictions.

How Your Care Team Prepares to Share Your Home

A high-quality, experienced care team should understand and be sensitive to the intense emotions associated with a diagnosis of ALS. Having a care team come into your home may be an additional source of anxiety for both you and your family; therefore, the team members are often patient and respectful of the varying feelings and responses that can occur:



Michael Macekura shares a special bond with his BAYADA Clinical Manager Deb Armus, RN.

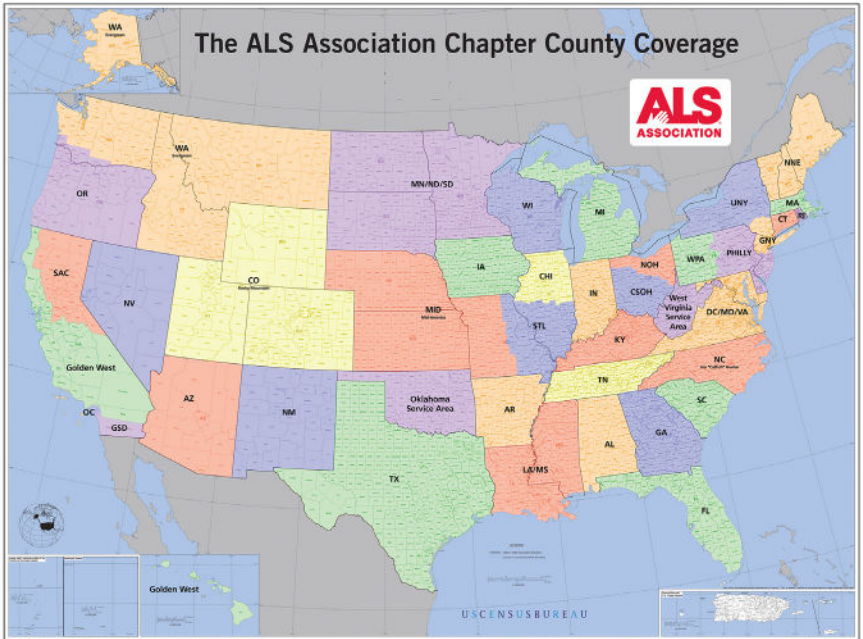
- When you were diagnosed with ALS, it's likely that both you and your loved ones experienced a number of different emotions such as shock, denial, fear, grief, guilt, anger, resentment, or anxiety. Perhaps you felt overwhelmed and experienced a loss of control. Each member of your family may have reacted differently to the situation.
- As your disease progresses, you and your family may experience those feelings all over again.
- Periods of sadness and anger are appropriate and normal.
- Denial is a defense mechanism that may be a natural response to grieving any type of loss.
- Feelings of isolation and detachment may occur because you may feel that no one else has the same experience.

Many people with ALS still find joy and contentment in their lives—just in different ways. To help cope with your diagnosis and live your life to the fullest, your care team may encourage you and your family to:

- Seek support from loved ones and health care professionals
- Share and receive support from others who have been in similar situations
- Express your concerns; open discussions can help reduce anxiety and encourage conversation
- Explore positive coping methods and outlets that may help you relax and communicate better, such as drawing pictures, meditating, listening to soothing music, or keeping a journal
- Participate in activities as much as possible to avoid feelings of isolation

About The ALS Association

The ALS Association is the only national non-profit organization fighting Lou Gehrig's Disease on every front. By leading the way in global research, providing assistance for people with ALS through a nationwide network of chapters, coordinating multidisciplinary care through certified clinical care centers, and fostering government partnerships, The ALS Association builds hope and enhances quality of life while aggressively searching for new treatments and a cure. For more information about The ALS Association, visit www.alsa.org.



For information about The ALS Association chapter in your area, visit: <http://www.alsa.org/community/chapters/chapters.html>

Glossary of Health Care Terms

AAC (augmentative/alternative communication) - Any mode of communication other than speech.

ADLs - An abbreviation for “activities of daily living.” It refers to routine actions that people normally take on their own behalf, such as bathing, dressing, toileting, feeding themselves, and more. Persons who are disabled, ill, or recovering from illness or surgery may require assistance with ADLs.

Advance directives - Instructions regarding the type and duration of life-sustaining treatment that an individual desires should they become terminally or irreversibly ill, and unable to communicate their wishes at that time. Typically refers to documents that are prepared such as a “living will” and “durable power of attorney.”

Aphagia - The inability to swallow.

Aphasia - An impairment in one’s ability to communicate; it may be either “receptive” or “expressive.” Receptive aphasia refers to difficulty understanding others’ speech. Expressive aphasia refers to difficulty forming words and communicating verbally.

Apnea - Pauses in breathing. Clients may experience intermittent periods of apnea due to underlying illnesses or defects. When breathing ceases and does not begin again spontaneously, the client is said to have had a “respiratory arrest.”

Aspiration - Breathing in or inhaling a foreign object.

Assessment procedures - This is the clinical assessment performed by the clinical manager on the first client visit. If home health aide services are needed, the client’s care plan is derived from the clinical manager’s assessment. If skilled services, such as nursing or therapy, are required, the care plan is developed from the physician’s plan of treatment as well as the clinical manager’s assessment.

Caregiver or caretaker - A relative, neighbor, or guardian who is a support person for a client (see also “primary caretaker”).

Certified nursing assistant (CNA) - A person who assists with the delivery of nursing care in many different health care settings (including the home) by performing basic nursing tasks under the supervision of a registered nurse (RN) or a licensed practical/vocational nurse (LPN/LVN); CNAs must complete a state-approved training course and pass the state’s certification examination.

Community Health Accreditation Partner (CHAP) - An independent, nonprofit, accrediting body with the regulatory authority to audit agencies to determine if they meet the Medicare Conditions of Participation and the CMS Quality Standards.

Client care plan - A customized plan of care services prepared by the client's clinical manager to meet the client's needs.

Client chart - Preferred term for client file or home care record. The client chart has three parts: the office client file, the home chart, and the computer client file.

Client - Preferred terminology to "patient," but interchangeable.

Client services manager - Home health care manager or coordinator who provides customer service such as scheduling and care coordination.

Clinical manager - The term used when referring to an RN providing nursing supervision in the home.

Commode - A portable toilet consisting of a frame, toilet seat and cover, and a bucket; typically placed near a client who cannot walk to the bathroom for toileting.

Continence - Adequate functioning of the urinary bladder or bowels, exhibited as the ability to retain urine or stool and recognize an urge to urinate or defecate.

CPR - Abbreviation for "cardio-pulmonary resuscitation." CPR is a combination of rescue breathing and chest compressions performed on individuals whose hearts have stopped beating.

Discharge planners - Persons employed by a hospital, skilled nursing facility, home care agency, or sometimes, by an insurance company, to oversee the process of discharge from a facility to home. Discharge planners are usually nurses or social workers. They explore clients' health care coverage, make arrangements for care at home, refer clients to other resources in the community, and arrange for needed equipment and supplies.

Durable medical equipment - Medical equipment (such as a hospital bed or power wheelchair) that is ordered by a doctor for use in the home and that will be used for an extended period of time; Medicare covers a portion of the cost.

Dysarthria - A group of speech disorders that affect the muscles involved in speaking.

Dyspnea - The feeling associated with impaired breathing; also known as shortness of breath.

Edema - Accumulation of fluid in a body tissue, appearing as swelling in the affected area. Severe generalized edema, also called anasarca, sometimes appears as fluid leakage onto the skin surface.

Employment (registry) agency - An agency that provides the names of nurses and nurse assistants who are available to provide home care; the client contracts with, and pays, the care provider directly.

Fasciculation - Involuntary muscle twitching and contractions. Often an early symptom of ALS, it is described as an irritating sensation.

Field nurse - An RN or LPN who provides nursing care to the client in the home.

Field staff - Term used for all nurses, aides, and therapists who provide direct care to clients in their homes.

Fine motor function - The coordination of muscles, bones, and nerves to produce small, precise movements.

Foley catheter - Used for urinary incontinence in males and females. Also known as “indwelling catheter” or “indwelling urinary catheter,” the Foley catheter is a flexible latex, silicone, or rubber tube that is passed through the urethra into the urinary bladder. A balloon at the tip of the catheter may be inflated once inside the bladder to hold the catheter in place. The end of the catheter that is outside of the body may be attached to a drainage bag.

Gastrostomy tube (G-tube) - A feeding tube inserted through the abdomen that delivers nutrition directly into the stomach.

Gross motor function - Refers to large movements of the body such as walking, running, sitting, crawling, and other activities. They are much less precise movements than those associated with fine motor function.

Home health care agency - A public or private organization that may provide assistive care, skilled nursing, and other therapeutic services to clients in their own homes.

Home Health Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey - Also known as the patient experience of care survey, a national survey that asks consumers about their experiences with Medicare-certified home health agencies; survey results are publically reported on Medicare.gov.

Home health aide - A person trained to provide non-medical services—including assistance with personal care—to clients in their homes. The type and amount of training that home health aides receive varies from state to state.

Homebound - Refers to clients whose physical health makes it a taxing effort to leave home for more than short periods of time. Being considered “homebound” is one of the eligibility criteria for using the Medicare home health benefit.

Hospice - A philosophy of care for terminally ill individuals (with a life expectancy of six months or less) which stresses family-focused care, comfort measures rather than cure, and attention to the emotional, social, and spiritual needs of the client and family. Hospice care neither hastens nor attempts to delay death. Hospice care is provided in a variety of settings, including clients' homes, nursing homes, hospital palliative care units, or freestanding hospice facilities.

Hoyer lift - A hydraulic device consisting of a frame and canvas sling for transferring clients.

Incontinence - Uncontrolled urination or defecation due either to an inability to retain urine or stool, or inability to recognize an urge to urinate or defecate.

Instrumental activities of daily living (IADLs) - More complex tasks that a person must perform routinely in order to live independently, such as paying bills, using the telephone, taking medication, and doing laundry (see also "ADLs").

Intermittent care - Nursing and therapy care services provided on a short-term basis to help recover from an illness, injury, or surgery. It is primarily provided under the Medicare home health benefit.

Jejunostomy tube (J-tube) - A feeding tube inserted through the abdomen that delivers nutrition directly into the jejunum or small intestine.

Jejunostomy - A surgically created opening from the jejunum onto the surface of the abdomen to create a route for tube feedings in some clients.

Jejunum - The portion of the small intestine located between the duodenum and the ileum, in the upper abdominal area.

Joint Commission on Accreditation of Health Care Organizations (JCAHO or "joint commission") - JCAHO is an organization that establishes quality standards for hospitals, home health agencies, and other health care organizations. Accreditation by JCAHO is voluntary and organizations that wish to be accredited must meet JCAHO standards. Organizations that are awarded JCAHO accreditation are deemed as quality health care organizations.

Licensed home health agency - A home health agency that is licensed by the state to provide skilled and assistive (personal) care services.

Living will - A type of advance directive, in which an individual specifies the type and duration of life-sustaining treatment that he/she desires should he/she become terminally or irreversibly ill and be unable to communicate those wishes.

LPN - Abbreviation for "licensed practical nurse."

LVN - Abbreviation for “licensed vocational nurse.”

Medicaid - State programs of medical assistance for individuals who meet income eligibility requirements.

Medicare - The federally mandated program of health care coverage for persons age 65 and older; persons who are defined for social security purposes as “disabled” for at least two years; and certain other special cases. Medicare part “A” coverage (commonly referred to as “hospital insurance”) is provided to eligible individuals at no cost and covers hospitalization, some inpatient care in a skilled nursing facility, home health care, and hospice care. Medicare part “B” coverage (commonly referred to as “medical insurance”) is optional; a premium is charged to beneficiaries who desire it. It covers physician services, outpatient hospital services, durable medical equipment, and a number of other supplies and services not covered by Medicare part “A.”

Medicare-certified home health agency - An agency that meets the conditions of participation for home health and/or hospice published in the Federal Register, and has been approved through the state survey process. Only Medicare-certified agencies may bill Medicare for covered services provided to its beneficiaries.

Needs assessment - A formal evaluation of the client’s needs, abilities, and disabilities that is usually done by the case manager and that forms the basis for the client’s care plan.

Nurse’s aide - An unlicensed care provider who provides personal care and other duties in a facility such as a hospital or nursing home. The qualifications of a nurse’s aide differ from those of a home health aide and are often defined by state law. The terms “nurse’s aide” and “home health aide” are not interchangeable.

Occupational therapist (OT) - A licensed health care professional who works with people needing specialized assistance performing daily activities, helping them develop, recover, and improve the skills needed for daily living. They assess the client’s condition and make recommendations focused on adapting the environment, modifying the task, teaching the skill, and educating the client and family to increase participation in, and performance of, daily activities. For example, the OT may recommend braces to lessen muscle strain and suggest equipment such as beds, wheelchairs, and seating devices that will best serve the client’s needs. The OT may provide ongoing assessments as the disease progresses and the client’s needs change.

Palliative care - Used to make the effects of something such as an illness less painful, harmful, or harsh. Palliative care is for anyone with a serious or life-limiting illness.

Payor - Person or other party responsible for payment.

Personal care services - Also known as "personal care assistance" and "home health aide services." Personal care services are provided by home health aides and include help with bathing, mobility, feeding, and toileting (ADLs). (See "home health aide" for further clarification.)

Physical therapist (PT) - A licensed health care professional who uses treatment techniques to help reduce pain, promote mobility, and restore function. Early after a client's diagnosis, a PT typically assesses the client's condition and need for mobility equipment such as lifts and wheelchairs. The PT may provide ongoing assessments as the disease progresses and the client's needs change. They may also develop a range of motion program (if appropriate) and teach the family transfer techniques for the safety and comfort of the client and caregiver.

Primary caretaker - Also known as "primary caregiver," the main personal support to the client (typically a relative, neighbor, or guardian) who is able and willing to assume full responsibility for the client's care in the absence of professional staff in the home.

Primary insurance - Also referred to as "primary payor," the health insurance policy that will be billed before any other for services provided.

Primary nurse - A field RN or LPN who may be delegated an administrative and/or enhanced clinical role for a case to which she/he has been assigned. The primary nurse collaborates with the clinical manager to ensure a coordinated plan of care.

Private services - Refers to care that is paid for privately, not by a governmental organization such as Medicare or Medicaid. Usually refers to long-term, ongoing care, but may include short-term, intermittent care.

Range of motion exercises - Exercises that move joints through the various motions as appropriate. In "active" range of motion, the client independently performs the exercises. In "passive" range of motion, the client is assisted by another person.

Respiratory therapy - A health care specialty that focuses on helping people to regain or maintain lung function through the use of exercises and treatments.

Respite care - Services provided to relieve the caregiver.

Resuscitation - Revival after apparent death. Resuscitation may involve rescue breathing alone, if the client has stopped breathing but his/her heart continues beating. Both rescue breathing and external compression of the heart are used in resuscitation when the client has stopped breathing and is pulseless (ie, the heart has stopped beating). The combination of rescue breathing and chest compressions is called "CPR."

ROM - Abbreviation for "range of motion."

Registered Nurse (RN) - A health professional licensed by the state; trained to administer treatments, perform tests, and educate and support patients.

Shower seat/chair - A chair designed to fit in a bathtub or shower stall used by clients who are unsteady on their feet or have restricted mobility.

Skilled care - Care provided by a health care licensed professional (such as a nurse, physical therapist, occupational therapist, respiratory therapist, or speech language pathologist); one of two basic types of home care services (see also assistive care).

Skilled nursing services - Health care services provided by a registered nurse or licensed practical nurse for the purpose of restoring and maintaining the client's maximal level of function and health. Services may include tracheostomy and ventilator care, wound care, respiratory treatments, feeding tube care, medication administration, and more.

Speech Language Pathologist (SLP) - A clinician who evaluates and diagnoses communication and swallowing disorders in infants through the elderly.

Spasticity - Refers to spasms that commonly occur when ambulation becomes difficult. Spasms are not always painful, but may cause painful cramps and tired muscles, and can limit the use of hands and legs. It can also include jaw spasms which can make swallowing, chewing, and talking painful.

Stair glide - A chair that attaches to a rail allowing it to glide up and down a staircase.

State Health Insurance Assistance Programs (SHIPs) - Free, in depth, one-on-one insurance counseling and assistance to Medicare beneficiaries, their families, friends, and caregivers.

State survey agency - The agency that inspects and certifies home health agencies to provide Medicare services and approves them to participate in Medicaid programs.

Suctioning -The removal of fluids from an organ or body cavity by way of a tube or catheter and a mechanical device that creates negative pressure (suction).

Texas catheter - Also known as "condom catheter," a type of urinary drainage device used for urinary incontinence in males. It consists of an adhesive condom-like sheath with a drainage tube which may be attached to a drainage bag.

Trachea - Also known as windpipe.

Tracheostomy - A surgically created opening in the trachea onto the surface of the neck to aid in breathing. A metal or plastic tube is inserted into the opening and is secured with flexible ties fastened around the client's neck. Loss of the tube by coughing or inadequate fastening of the ties is an emergency.

Transfer - Move from one place to another, such as from bed to wheelchair or wheelchair to commode.

Transfer board - A board used to decrease friction from bed sheets when moving clients from bed to another flat surface, such as a stretcher.

Tube feeding - The administration of a nutrient solution through a tube into the stomach or a portion of the small intestine.

Ventilator - A mechanical device that helps inflate, and in some cases, deflate, the client's lungs for respiration.

Visit - Unit of service, up to 24 hours (also referred to as a shift). A typical visit is from one half to two hours during which time a designated care activity is performed. For example, a nursing "visit" might involve wound care or other treatment; a typical home health aide "visit" involves assisting with ADLs.

Walker - A lightweight frame that a client uses to assist with independent ambulation by moving the device ahead of each step and using it for support and balance.

