



The ALS Home Health and Durable Medical Equipment Medical Standard Expert

Consensus Guideline

PREFACE

This national ALS Home Health and Durable Medical Equipment Medical Standard Expert Consensus Guidance document was developed in conjunction with the American Association of Neuromuscular Medicine (AANEM). The document lists medically indicated services and equipment for the care of persons with amyotrophic lateral sclerosis (ALS). This work builds on a scoping literature review published in *Muscle & Nerve* and on patient and professional stakeholder interviews.¹ This project received initial approval to proceed by the AANEM Practice Issues Review Panel in 2020. It expands on the 2024 National Academies of Sciences, Engineering, and Medicine report “Living With ALS” by providing detailed recommendations on home-based care, services, and equipment needed by persons with ALS as informed by the patient and caregiver community and an expert clinician panel.² This document outlines the minimum standards for home care to support improved outcomes for individuals with ALS. It includes a list of services and equipment considered medically necessary, which may be used by clinicians, payers, home health agencies, and ALS advocates for coverage decisions. Although not fully comprehensive, the list provides a foundation for care planning and acknowledges that many patients will require additional services and items depending on individual needs.

1 INTRODUCTION

Amyotrophic lateral sclerosis (ALS) is a deadly, chronic, progressive neuromuscular disease characterized by increasing needs for services and equipment to maintain life, independence, and dignity. Most persons with ALS remain in their own homes throughout the disease course; only a minority are cared for long term in a medical facility. In order to safely remain in the home, most individuals with ALS require home care and durable medical equipment (DME); however, access to these critically important needs is often challenged by delays and limits coverage provided by the Centers for Medicare & Medicaid Services (CMS) and commercial payers.¹ Current US ALS care guidelines focus on clinic-based multidisciplinary and pharmacological

management, and until this point there has not been a US guidance document that expresses what services and equipment are medically indicated for ALS patients in their homes. This guideline was created to address this gap and thereby facilitate the care of ALS patients in their homes.

The median survival from diagnosis to death in the US for individuals with ALS is 14 to 17 months,^{3,4} with an interquartile range of 9 to 31 months, and the rate of progression is generally rapid and often too fast for the current reactive US payer system to cover equipment and services in an effective manner. Given the rapid rate of disease progression, quarterly evaluations are appropriate for most patients. Current payer coverage practices allow for provision of equipment and services only after function has been lost instead of being based on anticipated functional decline. This, combined with processing times that are often months long, frequently results in delivery of equipment and services that no longer match the constantly evolving needs of the patient. The shortened prior authorization process that CMS will require beginning in January 2026 will help reduce delays, but it does not address the reactive versus predictive ordering of covered services.

The progressive nature of ALS determines future loss of function, and matching the equipment and services with what the patient needs as symptoms are developing, rather than after they have developed, would serve them better. At the same time, current payer systems do not provide sustained home health services for the duration of the disease. The current home health coverage of 21 days of service is too short for what ALS patients need, and an expectation of improvement of function to extend coverage is unrealistic and inappropriate. The progressive nature of ALS makes assumptions about the future loss of function certain, and matching the provision of equipment and services with the times they are needed, rather than after they were needed, would better serve patients. ALS care depends on both family and paid caregivers, and there is a need for increased resources to train and sustain both groups.

Persons with ALS and their caregivers describe the current resources and services that are provided as largely insufficient because the inadequate approach to care and limited access leaves their overall needs unmet. Community-based patient organizations attempt to close the gaps in service and add valuable support but lack the resources to address all the deficits. In addition, access to home health services and DME may be limited by several factors that fall

outside the scope of this guidance document, such as geographical inaccessibility, language barriers, financial barriers, and a lack of adequate insurance.

Effective care for an individual with ALS-related disability often depends on close collaboration between family and professional caregivers. However, widespread workforce shortages in home health care have resulted in reduced access to professional caregivers who have the knowledge and experience that are required to meet the needs of individuals with this disease. Just-in-time training opportunities to address the specialized needs of persons with ALS—for example, assistance with low-tech and high-tech communication aids—are limited and underutilized by this workforce.

In summary, it is our expert opinion that equipment and services should be provided based on what is expected to be needed, given the disease's known trajectory, to ensure patient safety and maximize the benefit from the equipment. Therapy services should be made available to meet the needs of the patient and help them maintain function and sustain independent living. DME is also essential to ensure safety and reduce costly and common secondary complications. Skilled nursing services should be provided for persons who require specialized equipment and assistance to breathe or maintain nutrition. Attendant care should be provided to allow for basic hygiene needs and to ensure the patient's health and dignity.

HOME HEALTH SERVICES FOR PEOPLE WITH ALS

ALS is a progressive neurodegenerative disease that requires comprehensive and adaptive home health care strategies. The recommendations provided in this guideline aim to improve the quality of life for people living with ALS by ensuring that home health services are both effective and responsive to the evolving needs of the patient. Home health services should also be provided with consideration of the needs of family caregivers.

1 General considerations for both ALS clinics and home care teams

1.1 Comprehensive functional assessment

1.1.1 A comprehensive initial assessment will determine the stage of ALS in the patient and tailor interventions appropriately. A simple three-stage clinical framework has been described in the rehabilitative literature and can be useful for purposes of communication regarding home health needs.⁵

Early-stage ALS is characterized by self-sufficiency, and in-home support for activities of daily living (ADLs) is not needed. The focus of services is preventive and remedial (education, voice banking, exercise to improve or maintain strength, flexibility, and function).

Middle stage ALS is marked by declining mobility and self-care abilities, necessitating compensatory strategies and DME, introduction of home health services, the early use of noninvasive ventilation when appropriate, and assistance with some ADLs.

Late-stage ALS is characterized by increasing functional dependence. It involves intensive home health care needs, including respiratory support, feeding assistance, and support for most ADLs. Compensatory strategies and prevention of secondary complications (falls, aspiration, wounds) are paramount at this stage.

1.1.2 The patient's condition should be reassessed regularly to ensure timely adjustments to the care plan as the disease progresses and anticipate impending care or equipment needs to adequately prepare patient and caregiver.

1.2 Screen for veteran status

Intake assessment should include screening for military veteran status; all persons with ALS with history of >90 days active-duty status should be referred to establish care and benefits with the Veterans Health Administration and Veterans Benefits Administration.

1.3 Establishment and reassessment of goals for care and priority needs

1.3.1 The patient's goals of care and priorities should be elicited and documented quarterly.

1.3.2 The caregiver's needs and preferences should also be elicited and considered.

1.3.3 Unnecessary institutionalization of a patient with disability should be avoided, and the patient should be informed about home health care options.

1.4 Palliative care and advance care planning

1.4.1 Education about end-of-life care decisions to enable informed decisions should be provided in a timely and sensitive manner and in collaboration with a palliative care team, when available, and the patient's decisions and preferences for end-of-life care should be communicated clearly with all parties involved, including resources such as do-not-attempt-resuscitation orders.

1.4.2 Hospice services should be offered once a patient meets eligibility criteria, when this is in alignment with the patient's goals.

2 Care coordination between ALS clinic and home care teams

2.1 A method for ongoing communication should be established between the clinic-based and home care teams as soon as home care is initiated. This coordinated care team should include members from the clinic-based and home care teams and comprise neuromuscular specialists (neurologists and/or physiatrists), primary care physicians, advanced practice providers, nurses, social workers, respiratory therapists, occupational therapists, physical therapists, speech-language pathologists, and dietitians.

2.2 Regular communications should occur with adequate frequency within the coordinated care team to review the patient's status, with input from the patient and family caregivers, and to update the care plan.

2.3 A means of communicating urgent concerns should be established within the coordinated care team.

2.4 Specialized interdisciplinary clinic-based ALS care should be continued in parallel with skilled home care services. Payers should reimburse both in-clinic and home health therapies when both are indicated. To ensure continuity of care, consideration should be made for telehealth appointments when the patient is no longer able to attend in-person clinic visits.

3 Medically necessary home care services for persons with ALS

3.1 General principles

3.1.1 Given the anticipated disease progression of ALS as well as anticipated accessibility-related and DME needs, skilled home care services should be deemed medically necessary in ALS regardless of the patient's homebound status.

3.2 Nursing care

3.2.1 Skilled nursing care should be available for patients requiring complex care (e.g., tracheostomy and ventilator management; nutrition through gastrostomy tube; skin care, including prevention and management of pressure ulcers).

3.2.2 Nursing staff in the inpatient, outpatient, and home care settings should be adequately trained to provide care. Online ALS-specific training resources (see Resources section) for just-in-time training are recommended.

3.2.3 Nursing staff in all care settings should provide hands-on training and education to family caregivers to support the acquisition of necessary skills so they can safely participate in all aspects of the patient's care.

3.2.4 Home nursing staff should monitor the patient's weight trends and should contact the specialty ALS clinical team to request dietitian consultation for any unintentional weight change, in particular in the instance of a weight $>5\%$ of baseline body weight.

3.2.5 Nursing staff should work with respiratory therapy professionals to support the optimal use of respiratory devices and communicate to the ALS team if medical issues develop (e.g., sialorrhea, anxiety) that may interfere with use of devices and require further follow-up.

3.2.6 The frequency and duration of home nursing visits in a patient's plan of care should be based on medical necessity and should not be limited on the basis of perceived coverage limits.

3.3 Home health aides

3.3.1 The development of resources for persons with ALS and caregivers is needed to assist families in locating, recruiting, interviewing, and hiring paid caregivers and to ensure that selected personnel possess the necessary training and experience.

3.3.2 Before providing care to persons with ALS, home health aides should be provided with adequate training. ALS-specific training resources for just-in-time training are available (see Resources).

3.3.3 Home health aides are required for the care of patients with ALS in the home and should be covered as a necessary health care expenditure when prescribed.

3.3.4 The frequency and duration of home health aide visits in a patient's plan of care should be based on medical necessity and should not be limited on the basis of perceived coverage limits.

3.4 Physical and occupational therapy

3.4.1 Home therapies should be offered for patients at any stage who would benefit from evaluation in the home setting for therapeutic exercise, equipment, caregiver training, or home modifications to enhance accessibility and safety.

3.4.2 Persons with ALS should have access to specialty ALS clinic therapists and home health therapists simultaneously because these are not duplicative services. Payers should provide reimbursement for both in-clinic and home health therapies when both are indicated. Patients enrolled in home health therapies who then require specialty in-clinic services (e.g., a wheelchair clinic or customized equipment) should not have to be discharged from home health therapies to do so.

3.4.3 Home therapists should receive basic ALS-relevant education, including adequate documentation of maintenance programs, to comply with insurance requirements for continued therapy coverage.

3.4.4 Home health and ALS specialty clinic therapists should communicate regarding interval changes in function that affect needs for mobility aids, such as wheelchairs, lifts, and specialized beds.

3.5 Speech-language pathology

3.5.1 Speech-language pathology referrals should be included at the initiation of home health services for all patients with ALS, regardless of the presence of speech or swallow impairments at the time of referral. This permits screening for subclinical impairments, education, preparation for an anticipated decline in communication abilities, and support for voice and message banking or the setting up of artificial intelligence-generated voice and/or augmentative and alternative communication devices.

3.5.2 Home health speech-language pathologists should conduct an in-person evaluation and make referrals for instrumental assessments of swallow function when indicated and in alignment with the patient's goals of care.

3.5.3 Home health speech-language pathologists should offer interventions and recommendations to optimize efficiency and safety of swallowing in alignment with the patient's goals of care. They should communicate and collaborate with the ALS clinic team physician when needed (e.g., for management of sialorrhea or when modification of medications is needed because of an inability to swallow).

3.5.4 When changes in swallow function are noted, home health speech-language pathologists should notify the ALS clinic team to request that a registered dietitian be consulted for dietary adjustments as dysphagia progresses and provide nutritional assessments and meal planning tailored to the patient's needs with consistencies that align with the patient's goals of care.

3.5.5 Home health speech-language pathologists should assess speech and provide speech therapy services to address dysarthria, dysphonia, and all other communication challenges and provide compensatory cognitive tools and strategies as indicated.

3.5.6 Home health speech-language pathologists should facilitate (or make referrals for) early access and training in low-tech (e.g., alphabet board, writing board), at a minimum, and high-tech assistive communication devices (e.g., speech-generating devices) as needed and if desired, and ensure proper training for their use.

3.5.7 Home health speech-language pathologists should offer cognitive-linguistic screening and provide compensatory cognitive tools and strategies as indicated.

3.5.8 Persons with ALS should be able to access specialty ALS clinic therapists and home health therapists simultaneously because these are not duplicative services. CMS and commercial insurers should provide reimbursement for both in-clinic and home health therapies when delivered simultaneously. Patients enrolled in home health therapies who then require specialty in-clinic services (e.g., augmentative and alternative communication) should not have to be discharged from home health therapies to do so.

3.6 Respiratory therapy

3.6.1 Noninvasive ventilation is a life-sustaining therapy for persons with ALS. Urgent approval and delivery of equipment (<72 hours) is necessary to avoid adverse events, such as hospitalization or death.

3.6.2 Respiratory DME vendors should provide education and supplies for patients requiring complex respiratory support, including, but not limited to, noninvasive ventilatory support, pulmonary hygiene, tracheostomy care, and ventilator management.

3.6.3 Respiratory DME vendors should ensure that respiratory therapists deliver comprehensive training to persons with ALS and caregivers on all equipment provided, including, but not limited to, respiratory assist devices, cough assist devices, suctioning equipment, and tracheostomy supplies. These clinicians should alert the ALS clinic when patients are unable to tolerate the use of a respiratory assist device despite adjustments and troubleshooting performed in the home.

3.6.4 Persons with ALS and families should be provided with contact information for 24/7 support for urgent supply or equipment concerns. Licensed clinicians should be available 24/7 for ventilator-related adjustments or concerns. Given the critical nature of respiratory equipment for persons with neuromuscular respiratory weakness, supply or equipment concerns must be resolved promptly.

3.6.5 Respiratory DME companies should provide modems and modem connectivity with issued equipment to permit uploading of data from respiratory assist devices to the supervising clinic and clinicians if medically indicated.

3.6.6 Respiratory DME companies should ensure periodic assessments of compliance with issued equipment, quarterly or as recommended by the ordering provider.

3.7 Nutritional support services

3.7.1 The patient's weight and nutritional status should be monitored, and appropriate measures, including nutrition counseling on diet modifications, should be taken to maintain weight.

3.7.2 For persons with ALS who cannot maintain their weight adequately through diet, nutrition counseling by a credentialed clinician, and oral nutrition supplements, should be offered/provided.

3.7.3 If a home infusion company is providing tube feeds, they should ensure that a credentialed clinician provides an assessment of nutritional needs as well as education, training, and management of feeding tubes (e.g., percutaneous endoscopic gastrostomy/radiologically inserted gastrostomy tubes), formula, and supplies.

3.8 Social work

3.8.1 Home health social workers should address financial challenges by educating families on available resources in their community (e.g., Medicaid, Supplemental Nutrition Assistance Program, long-term care planning).

3.8.2 Home health social workers should provide recommendations related to external funding sources, such as grants or fundraising, to support long-term care needs.

3.8.3 Home health social workers should provide information on community resources for home modifications to enhance accessibility and safety, including the installation of ramps and grab bars.

3.8.4 Home health social workers should refer patients and caregivers to local for-profit organizations or nonprofit organizations that provide equipment loans or grants for noncovered DME or services.

3.8.5 Home health social workers should provide counseling or referrals to community resources to support emotional and mental health, such as support groups or counseling for patients; caregivers; and family members, including children.

3.8.6 Home health social workers should ensure that patients and families receive adequate support during end-of-life care. This may include referral to community-based organizations for end-of-life education and resources, options for home and inpatient end-of-life care, and education about what types of home support and services are available through insurers or private pay.

4 Recommendations for ALS clinics

4.1 Clinics should serve as a resource and provide education to enhance the knowledge and skills of caregivers and health care professionals on ALS topics.

5 DME for ALS home care

Table 1 includes common categories of medically indicated DME required to accommodate disability related to ALS in the home setting. Optimal care for persons with ALS is both proactive and anticipatory. Therefore, the provision of DME should occur before a loss of specific function necessitating its use occurs. Training in how to use the device safely and effectively should also be covered. Care should be individualized in accordance with the anticipated needs of the individual on the basis of their disease trajectory. The list in Table 1 is neither exhaustive nor prescriptive. Listed devices and home modifications are not equal and

interchangeable, and most patients do not require all equipment in the listed sequence. Future innovations in DME may necessitate modification of this list.

5.1 Essential DME: Nonrespiratory

The items included in Table 1 are medically indicated reusable devices or supplies used in a home setting to support the safety, comfort, and/or function of persons with ALS. Included items are considered essential if the lack of access would pose risk of bodily harm or secondary complications for the person with ALS (e.g., skin breakdown, falls, contractures) or their caregiver (e.g., lifting injury), or if a lack of equipment would result in loss of ability to perform basic self-care activities (e.g., bathing, dressing, toileting, functional transfers, feeding, continence).

Because of the anticipated progression of ALS and the significant risk of harm associated with delays or denials of provision of this equipment, it is recommended that the items on this list are considered indicated on the basis of a diagnosis of ALS alone, without loss of function being deemed a prerequisite. Provision of necessary equipment only after loss of function has occurred increases risk of injury and harm and furthermore places avoidable strain on patients, caregivers, clinicians, and the health care system in responding to secondary complications and crises. In addition, equipment that does not meet the needs of future loss of function may increase health care expenditures when new equipment must be ordered, or preventable hospitalizations result from inadequate equipment as the disease progresses. Any equipment should be provided with the supplies and consumables needed for its use.

DME suppliers should deliver prescribed DME in a clinically appropriate timeline, generally within 1 week of the date of prescription. Timelines for payer authorization of coverage should not result in harm to the patient.

Acknowledgments

We extend our sincere appreciation to the following people with ALS (PALS) and caregiver reviewers for their valuable feedback and contributions, which have helped shape and refine this guideline: Stacy Lewin Farber, MD; Todd Kelly; Layne Oliff; David S. Killoran; and Troy Fields.

Key members of the Organizing Committee include the task force chair, Björn Oskarsson, MD (Mayo Clinic), and methodologist, Megan A. Allyse, PhD. National stakeholders in amyotrophic lateral sclerosis (ALS) care—including the Western ALS Study Group; the ALS Network; and individual ALS advocates, including Daniel L. Doctoroff, Ady Barkan, and David Killoran—also were involved in the effort.

The Organizing Committee was formed and had its first meeting on September 22, 2023. Two members of the Practice Issues Review Panel volunteered to serve on the committee at large: Srikanth Muppudi, MD, Department of Neurology, Stanford Medicine, and Bharathi Swaminathan, MD, Physical Medicine and Rehabilitation (PM&R), Chicago Medical School. Other members include Ileana Howard, MD, PM&R, University of Washington; Jill Goslinga, MD, MPH, University of California, San Francisco; Dominic Ferrey, MD, Department of Neurology, University of California, San Diego; Maxwell Greene, MD, Department of Neurology, Stanford Medicine; Heather Young, PhD, RN, Betty Irene Moore School of Nursing, Family Caregiving Institute, University of California, Davis (UC Davis); Janice Bell, Betty Irene Moore School of Nursing, Family Caregiving Institute, UC Davis; Jennifer Mongoven, MPH, Associate Director of Operations, Family Caregiving Institute, UC Davis; Jessica Famula, MS, Family Caregiving Institute, UC Davis; Joyce Khowdee, OT, DOT, Center for Restorative Neurology, Loma Linda University Health; and Sara Feldman, PT, DPT, ATP, MDA/ALS Center of Hope, Temple University.

Abbreviations

ADLs, activities of daily living; ALS, amyotrophic lateral sclerosis; CMS, Centers for Medicaid & Medicare Services; DME, durable medical equipment

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TABLE 1. Durable Medical Equipment (DME) for ALS Home Care

| FUNCTION CATEGORY | ITEM, EQUIPMENT AND SUPPLIES |
|--------------------------------|---|
| Mobility & Transfer | <p>Transfer aids</p> <ul style="list-style-type: none">• Gait/transfer belt• Bed rail, transfer pole• Car door handle assist• Transfer board/pivot disc <p>Chairs</p> <ul style="list-style-type: none">• Recliner• Standing chair• Seat assist• Couch risers• Cushions <p>Lifts</p> <ul style="list-style-type: none">• Patient lift: motorized/electric/battery powered• Patient lift: hydraulic/hand pumped/manual (only rarely appropriate)• Lift sling• Barrier-free/ceiling-based lift/ceiling lift track system <p>Ambulation aids</p> <ul style="list-style-type: none">• Cane/hiking pole• Walker: standard walker; rolling walker; four-wheeled walker/rollator, including standard; platform/upright, all terrain• Hybrid rollator-transport chair <p>Stair navigation</p> <ul style="list-style-type: none">• Rails• Modified steps• Ramps• Stairglide• Lift• Elevator <p>Manual wheelchairs</p> <ul style="list-style-type: none">• Transport/companion• Standard/lightweight• Custom ultralight• Custom tilt-in-space• Cushions• Positioning/pressure relief elements |

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| | <p>Power mobility</p> <ul style="list-style-type: none"> • Power scooter • Folding portable power wheelchair • Complex rehab tech/custom PWC <ul style="list-style-type: none"> ◦ Base-front, mid-, or rear-wheel drive ◦ Seating: tilt, recline, tilt and recline, seat elevator, anterior tilt ◦ Controls: joystick, adapted joystick, alternate drive ◦ Positioning elements ◦ Assistant control <p>Home access</p> <ul style="list-style-type: none"> • Modular ramp for home entry • Lifts • Hand rails for stairs • Threshold ramp <p>Transportation</p> <ul style="list-style-type: none"> • Adapted vehicle appropriate for wheelchair and other equipment |
| Bed Mobility | <p>Bed equipment</p> <ul style="list-style-type: none"> • Bed positioning bolster/wedge • Bed rails/trapeze/ladder/side frames • Fully electric hospital bed • Laterally rotating mattress • Specialty mattress • Adaptation to the bed/extender for a hospital bed • Over-bed table |
| Bathing & Toileting | <p>Grooming/dressing</p> <ul style="list-style-type: none"> • Long-handled tools: reacher, dressing stick, long-handled comb/brush, long-handled shoehorn • Dressing aids: sock aid, bendable sock aid, button hook, leg lifter, zipper pull, zipper pull w/cord extender or ring • Adaptive clothing: hook-and-loop fastener, snaps, or magnets for buttoning shirts (long and short sleeved), pants, shorts • Undergarments, upper body: looped, magnetic, snap brassiere, bra, bralette • Undergarments, lower body: hook-and-loop fastener (front, sides) • Bed wedge and/or bed ladder for dressing at bed level |

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| | <p>Bathing</p> <ul style="list-style-type: none"> • Grab bar • Shower bench/seat, tub transfer bench, sliding shower chair with or without a swivel seat with or without arms • Tilt-in-space shower chair • Rolling shower-commode chair • Threshold ramps for access to shower stall • Hand-held shower, wash mitt, long-handled/bendable bathing sponge • No-rinse shower cap • Remodeling: walk-in shower, zero-entry/roll-in shower <p>Toileting</p> <ul style="list-style-type: none"> • Commode: 3-in-1 (bedside, over the toilet, in the shower), drop-arm commode, rolling shower commode chair • Raised toilet seat/toilet riser with arms • Grab bar/safety rail • Bides: electric or water powered, flat seat riser <p>Lifts</p> <ul style="list-style-type: none"> • Patient lift: ceiling mounted, free standing (electric/manual) w/split sling • Toilet lift: lift seat, uplift commode assist chair <p>Urinals/catheter systems</p> <ul style="list-style-type: none"> • Female: portable urinal, external catheter and urine collection system, funnel urinary cup • Male: external condom catheter, disposable portable john, portable urinal, spill-proof portable urinal • Supplies for suprapubic or external catheter <p>Barriers</p> <ul style="list-style-type: none"> • Pull-up brief/diaper, bladder pads (males/females), disposable or reusable underpads |
| Neck or Limb Function | <p>Cervical spine supports</p> <ul style="list-style-type: none"> • Soft collar, wire collar, rigid plastic collar <p>Orthotics for function: Upper extremity</p> <ul style="list-style-type: none"> • Adaptive equipment to accommodate functional grasp: universal cuffs, splints with cuffs to hold objects, custom-fabricated holders (e.g., razor, toothbrush) • Dorsal wrist cock-up splint with universal cuff • Dorsal-blocking wrist orthosis with universal cuff • Carpometacarpal support/opponens splint |

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| | <p>Orthotics for function: Lower extremity</p> <ul style="list-style-type: none"> • Molded ankle foot orthotic, dorsi-strap, toe-up • Special shoes with braces/shoe inserts to support feet <p>Orthotics for positioning: Upper extremity</p> <ul style="list-style-type: none"> • Finger splints • Resting hand orthosis (resting position or functional position) • Shoulder supports <p>Orthotics for positioning: Lower extremity</p> <ul style="list-style-type: none"> • Pressure relief ankle foot orthosis, ankle lateral support • Dynamic splints for contractures <p>Other medical</p> <ul style="list-style-type: none"> • Palm protector • Gloves for edema <p>Soft boots for skin protection</p> |
| Feeding & Food Preparation | <p>Feeding</p> <ul style="list-style-type: none"> • Adaptive equipment for food prep (bottle/jar/can openers: electric, under cabinet, manual, gripping material) • Adaptive (angled, lightweight, built-up, bendable) feeding utensils, looped utensils, foam tubing • Hydration: Hands-free bottle hydration system, insulated/stainless steel, with or without a mount; long straw; flexible straw; bite valve; flexi-mug; mug with handles; wedge cup with flow control (dysphagia cup); modified cup; adaptive holder; universal handle • Dining: Plate with raised/curved edge, plate/bumper guards • Nonslip materials to open jars and bottles; placemat, coaster, strips for added grip, straps/silicone adaptive aid, universal cuff • Robotic feeding systems, mobile arm support dynamic with elevation assist • Height-adjustable hospital/bed table • Pole to hold tube feeds at PWC level • Gastrostomy (PEG/RIG) tube/supplies (e.g., syringes, hoses, food, gauze) • Feeding formula, alternative nutrition, nutritional supplements <p>Thickener</p> |

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| | <p>Meal prep</p> <ul style="list-style-type: none"> • Rocker knife lightweight/heavy, T-grip, one-handed grip, angled • Cutting board with raised edges, with spike, L-shaped corners • Food processor, blender, instant pot, slow cooker |
| Accessibility of Electronic Devices | <p>Software</p> <ul style="list-style-type: none"> • Setting voice/remote controls for smartphone, tablet, TV • Environmental controls (e.g., thermostat, deadbolt) • Voice-activated virtual assistant technologies <p>Hardware</p> <ul style="list-style-type: none"> • Holders/mounts for devices • Microphone headset • Mouth stick/stylus <p>Mobile arm supports</p> |
| Communication | <p>Communication</p> <ul style="list-style-type: none"> • Caregiver call chimes/adapted call chimes <p>Low-tech AAC</p> <ul style="list-style-type: none"> • Eye gaze board • Communication board • Partner-assisted auditory scanning board, laser pointer • E-writer <p>High-tech AAC</p> <ul style="list-style-type: none"> • Voice amplifier • Speech-generating devices (including eye gaze) • Mounting systems • Switches, eye gaze, and other access tools <p>Voice and message banking (headset microphone)</p> <ul style="list-style-type: none"> • Smartphone and tablet • Features for hands-free communication • Text-to-speech apps for phone/tablet <p>Writing</p> <p>Adapted writing tools</p> |

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| Medication Management | Medication organizer Team management software/app |
| Emergency/Safety | Wearable medical alert device Generator/back-up power source |

Abbreviations: AAC, augmentative and alternative communication; PEG, percutaneous endoscopic gastrostomy; PWC, power wheelchair; RIG, radiologically inserted gastrostomy.

TABLE 2. Essential DME: Respiratory

| CATEGORY | VENTILATORY EQUIPMENT AND SUPPLIES |
|-------------------------|---|
| Ventilation | Respiratory assist device <ul style="list-style-type: none">• Noninvasive ventilator• Mouthpiece ventilator• Invasive ventilator Backup respiratory assist device Backup battery power Humidification system Masks and disposable supplies |
| Airway Clearance | Bag valve mask Mechanical insufflator–exsufflator (e.g., cough assist device) Portable suction Home suction |
| Other | Nebulizer Ventilatory strength trainers Tracheostomy supplies Oral hygiene/oral care supplies |

APPENDIX A

Resources

Outcome and Assessment Information Set home assessment:

<https://www.cms.gov/files/document/oasis-e-manual-final.pdf>

ALS Guide for Paid Caregivers: <https://www.youralsguide.com/als-caregiving.html>

Resources for Learning About ALS: <https://www.als.org/navigating-als/resources>