

Note: The forums have a search box at middle right of every page. Or ask and we can point you in the right direction. There is also a list of some places to shop/inquire on my profile in Albums.

Update: Newer iPhones and iPads that have a TrueDepth camera, like the iPhone X, XR and XS, and the iPad Pro, permit direct use of eye gaze (without a switch interface), and free supporting apps (that require iOS 12) are available for download. There are also eye gaze apps in the Google Play store for Android devices. Note that this technology is just coming of age and does not have all the robustness that an SGD (see below) would.

How to Get What You Need. The right equipment at the right time can help PALS live longer and more meaningfully. The process of obtaining DME and the reimbursement available varies widely by country, so the points below apply best to non-veterans who have Medicare and/or private insurance in the US.

If you receive services from the VA, check with your center as to how best to obtain the items below.

If you are outside the US, check with your national health service or other payor as to what equipment is reimbursed and from whom/how it is obtained. If you prefer other options, you can consider the information below. Those in countries where a full range of equipment is unavailable have the option to utilize a forwarding service in a country to which the equipment you need can be shipped.

The first questions to ask when considering a piece of equipment or medical supplies are:

- Do you need to buy new or will used suffice? If used could suffice, is it available person-to-person? Sometimes even new medical supplies are "freecycled" because someone no longer needs them, yet they are difficult to sell— check for the freecycle listing in your town. And Craigslist, neighborhood classifieds, NextDoor, etc. You can also post a "wanted" listing. Maybe your local ALSA or MDA chapter has a loaner (frequently the case for lifts and sometimes for power chairs).
- Does this require a prescription, apart from Craigslist and other person-to-person purchases?
- What is its retail value?

- What is its street value?
- If supplies, can you save by buying in bulk? Keep in mind that the largest size is not always the best deal.

Always compare apples to apples, e.g. if a gallon of No-Rinse Shampoo is \$25.99 and a three-pack of 16-oz bottles is \$18.99, you are getting a better deal on the three-pack. Amazon is a great place to compare prices across available sizes, as is eBay. Some items that it pays to shop in Amazon for include vitamins/supplements/OTC medications (it may pay to buy multi-packs); wipes, gauze, bandaids, sprays and other hygiene supplies; cervical collars, braces, other small durables like plastics; etc.

What is Durable Medical Equipment (DME)?

“Durable” applies to things like beds, lifts, commode chairs, wheelchairs and ventilators/BiPAP and is the opposite of “disposable,” which applies to things like wipes and gauze that are thrown away, or cervical collars, that are not very costly.

By Medicare’s definition, a DME item has to have a useful life of at three years, and most items become fully replaceable after five years at most. In the US, disposable items are generally not reimbursable except in conjunction with home or hospice care, and/or certain types of DME, e.g. tubing for tracheostomy care, masks for BiPAP use, etc. “Convenience items” like grab bars or toilet seats are hardly ever reimbursable, except possibly by Medicaid or the VA.

DME reimbursement is determined by the DME benefit in your policy, which usually entails a copay for purchase cost or monthly rental (usually 10% or 20% for in-network providers) up to an annual maximum for out-of-pocket expenses across all your copays. Reimbursable items typically require a prescription and/or prior authorization. Further justification such as chart notes and a letter from a clinician are increasingly required.

Frequently, decisions and recommendations by clinicians, salespeople, ATPs and organizations are influenced by two things: their convenience — it’s unavoidable that they know some people and options better than others— and money, which flows in various ways around the medical equipment world. Everyone wants to help you, but

it's human nature to want to do it their way.

It's *your* comfort, and, at the end of the day, your money that is at stake, so double-check the choices that may affect these. If someone says, "Most patients—" reframe your question more specifically, e.g. "Patients with my level of immobility? Patients that have already failed Product X?" If the answer boils down to, "We'll have to try...I'm not sure what will work best..." it's time to hit the Internet and at least satisfy yourself that no better answer exists.

You do not have to use the DME firm that your clinic recommends, or one at all; the vast majority of items are available for cash on line; some, such as suction machines and PAP masks, can very easily be cheaper via cash purchase than through insurance rental or purchase, especially when considering the value of your time in processing paperwork. Even with items that require an rx, such as BiPAP, you can purchase a machine on your own using a doctor's prescription just as for glasses or contacts.

As a general rule of thumb, it is often more cost-effective to at least consider obtaining third party reimbursement, aka insurance, when you are looking at big ticket items such as a new power wheelchair, new hospital bed, CoughAssist, oscillation device ("The Vest") or a ventilator that is more than a BiPAP, e.g. the Trilogy, Stellar or Astral, in other words any respiratory assist device that weighs more than a couple of pounds.

So then the question becomes what DME to use. Some patients first become aware of local DME suppliers, many of which are branches of national companies, at local ALSA or MDA events. While their sponsorship of these events and organizations is commendable, it is no substitute for the personal service you deserve. Medicare has a Web site where you can type in a particular piece of equipment and see what suppliers are in network in your area.

If you choose not to use a DME firm, you will forego "training" on the equipment and have to organize/pay for any necessary repairs yourself. "A la carte" repairs and upgrades for some equipment, even power wheelchairs, is increasingly available, especially in certain states, and through national resellers such as SpinLife that are building

repair networks.

As far as orientation to the equipment, in addition to brochures, "training" is often available free and on-demand, via videos on YouTube and manufacturer sites, PDFs on the Web (Google first; many excellent resources have been posted by others) and other resources. Or you can post questions here on the forums.

If you do seek reimbursement for an item, you can use any DME on your plan's list (you may incur greater costs or no coverage at all by going out of network; check your plan benefits summary).

Of DMEs that you can use, at least one of those suppliers can and should order equipment that you need, if they do not stock or routinely order it. Good DMEs are also skilled at obtaining reimbursement for equipment features that are a bit out of the ordinary, either by knowing how to justify them or how to get your OT, PT or doc to justify them. That may include "closer to nature" tube formulas like Kate Farms and Liquid Hope.

For some items, such as hospital beds and lifts, you will probably only be reimbursed a portion of the total cost because, for example, power lifts/beds are not always covered, so you will get reimbursed for what a manual lift costs.

When you are first diagnosed, you may need a cane, walker and/or manual wheelchair as the disease progresses. Medicare and private insurers will only pay for, essentially, one vehicle every five years, so you do not want to use that benefit on a manual chair, which is over ten times cheaper than a power chair. Likewise, although you might be able to make use of an electric scooter for a while, if you get it reimbursed through insurance, you likely won't be reimbursed for the power wheelchair you will ultimately need.

If you are in "traditional Medicare," most DME is rented, under a capped rental (13 months) after which you own the item. Medicare Advantage may even be more restrictive, e.g. continuing rental indefinitely.

Complex rehab power chairs, like PALS need, are an exception to

capped rental since they are customized to the person. However, every maintenance or service performed on the chair, including new batteries, which chairs usually need about every 12 months, may be billed separately. An assistive technology specialist from your DME firm or clinic will write up the order for your new chair.

Make sure the final paperwork (yes, you need to read it) includes tilt, recline, seat elevator (which some manufacturers subsidize for ALS patients in need if not reimbursable; ask your ATP) and elevating foot rests. You will also need a better cushion than the one that comes standard with the wheelchair, and probably a non-standard back cushion as well.

Although it is wise to plan ahead, since getting a script, authorization and the purchase/delivery process can take time, you can still wait until there are signs of trouble in a particular area. If you have trouble swallowing, yes, start looking into a PEG tube. If you have difficulty standing or walking, it's time to think about a wheelchair. But some PALS remain able to walk, talk and/or eat throughout their lives. And prices in some categories are declining as technology and production methods allow for lower prices and greater selection. So don't jump too soon.

I maintain a list of DME/medical supply Web sites on my Forum profile that are reputable and cheap enough to have sold me something. No one site or catalog is always the cheapest on every item so price-shopping saves money. Ironically, Amazon is cheap on some items and insanely expensive on others, because it mostly hosts other vendors' listings and those tend not to offer free shipping, whereas other Web sites frequently offer free shipping at a certain total order level.

Many clinics push a catalog formerly called Sammons Preston, now Patterson Medical. This catalog, ironically, is often the most expensive for common items. Its house brand, essentially repackaging other brands' designs, is called Rolyn Prest and it too is seldom the best deal. You will see many "repackaged" items available, e.g. from major catalogs such as Sunrise. The exact same item is often available under several different brand names, so shop around for the best price, including shipping and sales tax.

Some clinics stock items, large to small, that may help you and they will provide them directly, billing insurance if applicable. If your ALS clinic or ALSA/MDA chapter gives or lends you something, it may not be the best thing. If it doesn't work well, keep looking.

You will need a variety of medical "aids" and supplies for the bathroom, bedroom and more.

As the disease progresses, you will likely need a cervical collar (likely changing them out as you go). At the beginning a "medium density" soft collar from Amazon may suffice. Later, more structured products (plastic instead of foam) may be desirable. Some common collars to try include the Philadelphia, Aspen Vista, Headmaster, Trac Collar. Some also report success with Shane's brace.

Also re-evaluate the PALS' bed pillow periodically. For example, as neck muscles collapse, you may need a firmer, softer and/or more/less contoured pillow. Look for a foam "shoulder pillow." Latex and memory foam have different properties, and some foam is less supportive than others.

Ventilation. When a PALS' breathing is first affected by ALS, it is time for BiPAP, even if s/he is already on CPAP for sleep apnea. BiPAP ("Bi" referring to these two pressures) machines allow for a higher pressure when breathing in and a lower one breathing out, to work the muscles that control breathing less hard.

However, a traditional BiPAP mode is programmed to increase air flow (in Auto mode) only in the case of sleep-disordered breathing (reduced or no air flow), not any particular tidal volume. Therefore, most often recommended for PALS is a BiPAP that includes a backup rate (PC, T, ST, AVAPS or iVAPS modes) and "volume control" or "volume support" (iVAPS or AVAPS mode option) that adjusts the pressure according to how much air the patient is moving on her own.

The ideal mode and settings will definitely change as ALS progresses, and can be different depending on whether someone is asleep or awake; has a cold/congestion or not; etc. For instance, when someone is choking or coughing uncontrollably, shutting off the backup rate may be essential. There is no single lifelong recipe for any particular

machine. Thus, you should know how to make necessary changes; you can PM me or post to find how/why for your/your PALS' particular machine.

If you are interested, you can monitor your own data, either through Respironics' or Resmed's own software, or through a free open source app, such as Sleepyhead (the only app that works with Mac, Win, Linux, though it only works with certain models).

If oxygenation is an issue, though that is usually not the core problem in ALS (instead, it's too much CO₂ remaining in the body because you can't breathe it out), an oximeter can be connected to some of the newer BiPAPs and vents. You can also check the oxygen level any time with a finger clip oximeter such as is used at doctor's offices; these are fairly cheap and can be purchased on line. Until the end of life, supplemental oxygen is usually not used in ALS because more oxygen means more CO₂ to breathe out. However, in pneumonia, for example, it may be used.

Lift. Hydraulic [non-powered] lifts are still being sold, but unless your PALS is very, very light, you will want a powered lift that rolls across the floor, carrying your patient in a sling, then lifts or lowers her, using electricity, depending on the need, into bed, the toilet, a wheelchair or another kind of chair. Your MDA/ALSA chapter may have an indefinite loaner.

Some lifts fold for storage (Liko Light, Hoyer Advance, BestLift 350 and Invacare I-Lift); the Molift Smart folds and fits into a rolling case. There are also vertical systems "ceiling lifts" like Voyager where you install permanent or freestanding rail systems and a portable motor, attached to a sling, lifts the PALS.

When considering a lift, sling or railing system, always consider the future worst case scenario, e.g. the patient has no head control (head has to be propped by hand or a collar or a wheelchair/bed) and no torso control to stay upright.

Slings. Every journey with a lift begins with placing a patient in a sling. The most common sling used is a divided-leg ("U sling"), often made of polyester mesh, that can be used for bathing, toileting and

transfers alike. Many PALS need the “head support” (really, back support) option. Avoid “toileting slings” that completely cover the lower torso except for a toilet-use hole.

Most slings work with any brand of lift though sizing may vary; however, a sling designed for a stander lift (one that supports the patient upright) will of course not work with a lift designed for seated transfers only.

Also, as disease progresses, avoid slings in which the arms cannot be held in by the sling, since the patient will be unable to hold them independently. As muscle atrophies, especially in the lower half, a PALS may need a smaller size sling than at first, irrespective of weight.

Bed. For a hospital bed, seriously consider 80” for anyone but a petite woman and 84” for a guy 6-ft or so +. Do not let anyone tell you that a “standard” 75-76” will suffice. You are going to have the head up a lot and the body will slip down. Transfers also require a runway.

Linak motors are often considered the gold standard; ask any supplier if your bed-to-be has one. Ideally, the bed control has four button pairs — head up/down, whole bed up/down, tilt up/down, legs up/down.

Mattress. If you start with a medical grade foam mattress for maximum reimbursement, you can add an air or gel overlay later, or a foam overlay earlier, or move to a low air loss/alternating air overlay as your condition worsens. It’s easier (and cheaper) to add overlays rather than replacing whole mattresses, but it also affords you more flexibility as well.

Assistive tech

As ALS progresses, you may be thinking about a help-summoning app for when the PALS is on their own, which could be as simple as a Home screen shortcut or a free app; a bed call button, which can be operated by voice, toe, finger, head — a means to monitor the PALS via Web, USB or Bluetooth camera with or without a speaker, etc. We have discussed all these on the forums, but also feel free to ask since

technology marches on.

iOS8 and later versions permit access to Siri without pressing buttons. Android permits voice recognition control as well. At this writing, the ALSA's assistive technology pages are seriously outdated. For example, they imply that a separate software purchase is necessary to be able to utilize a "virtual" (onscreen) keyboard. It is not, although apps that enable creation of custom keyboards are available.

Also, modern OS have text to speech (TTS) capability built in; you do not need to buy dedicated apps to have text read to you. If you do not like the default voices in your OS, snazzier ones are available for little money, for use in apps such as Voice Dream, or you can pay for books that are professionally narrated, from portals such as Audible. TTS apps like Voice Dream will work with any PDF, so you can go to the many sources of free ebooks in the public domain, and get PDFs that can be read to you, and/or automatically scrolled and highlighted in a style and speed of your choosing.

SGDs. Some PALS use dedicated eye gaze-activated "speech generating devices" such as Tobii and Dynavox for Windows (which are now one company, Tobii) and Eyegaze (Mac), but these systems are expensive, reimbursement can be a challenge (current regulations call for patients to relinquish their Medicare-funded devices when they enter hospice or long-term care, for example) and, by all accounts, difficult to calibrate as the PALS progresses.

As iOS devices (iPhone, iPad) and Android devices (Nexus, Galaxy, Lenovo, Moto, Pixel, etc.) evolve their operating systems to play well with switches and have built-in switch access, e.g. via head movement and being able to attach switches with even a single working muscle (e.g. forehead, cheek, jaw, tongue) via Bluetooth, SGDs are no longer as broadly applicable to PALS. And apps are being developed that will make switch interfaces, such as currently required, obsolete.

A switch can be used to interact with applications that can utilize "switch scanning," that is, automatically cycle through menu items, words, choices or letters (as with a virtual keyboard). Then, using a switch, the user makes a selection. For Mac and iOS users, atmac.org offers articles on apps and kludges. Or Google your platform/device +

“switch access” or “switch scanning.”

In other words, with modern TTS applications, anyone who can use any kind of switch, as opposed to eye gaze only, may be better off with a modern computing device rather than an SGD. However, for some patients, eye gaze is faster and easier than using a switch.

One way to check ability to use head movement/a head mouse as a switch is to enable the head movement setting in your favorite device, if/as applicable, and see what can be done with scanning, the speed of which is usually selectable.

Summing up. Obviously, this sticky won't cover all your needs. Post on the forums when you need help — someone else has been there! We can't post commercial links due to forum rules but you can PM if needed.