

# ALSinfo

*Essential information for the newly diagnosed!*

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## About

This is a living document and is updated frequently.  
You may share or copy this document freely in original form.

My thanks to Renee K. of National Jewish Health, Nikki J of ALS Forums and my daughter (and published author) Shannon Lawrence for input and editing.

If you want an updated copy, have suggestions or additional information please contact me at [GDKenoyer@gmail.com](mailto:GDKenoyer@gmail.com).

*Note: In its online pdf format the links in this document are active (clickable)*

## Introduction

If you've just been diagnosed with ALS you'll feel scared and unsure of what to do next. This is perfectly normal and will pass as you learn more.

**This document is intended to help you through that process.**



沉着 (calm)

## What To Do First

### Legal & Financial Stuff

The time after diagnosis is very emotional and you may not feel that you are up to this, but it is important to get the following into place:

- **Prior to diagnosis**, if possible, get life insurance and long-term care insurance.
- Make sure your will is clear and up to date or draft one if you've not already done so
- Advanced health care directive, also known as a Living Will<sup>\*</sup>. This document allows you to state clearly what medical interventions or treatments you want in certain situations, including a DNR order. You should talk with your doctor about this document to ensure you are clear on what different terms mean so that you fill it out according to what your wishes are.
  - There is an excellent guide that will help you define your wishes under different medical circumstances in the US. It is called "Five Wishes" and is available at <https://www.agingwithdignity.org>
  - Do Not Resuscitate: In the US., cardiopulmonary resuscitation (CPR) and advanced cardiac life support (ACLS) will not be performed if a valid written "DNR" order is present. Many US states do not recognize living wills or health care proxies in the prehospital setting and prehospital personnel in those areas may be required to initiate resuscitation measures unless a specific state sponsored form is appropriately filled out and cosigned by a physician

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*\*Items I use regularly are marked with \**

- Medical power of attorney\* (called Power of enduring guardianship in some countries). This document allows you to nominate someone that you trust to advocate for you with medical professionals if you either lose the intellectual ability to do so, or cannot communicate and sign for yourself. This person must only then carry out what has been signed by you in the advanced health directive.
- Durable power of attorney\*. This document allows you to nominate someone that you trust to operate your finances for you if you are unable to do so. For example if you lose the ability to sign documents, this person can do this for you.
- If you are covered by an employer life insurance check your policy for something called 'accelerated death benefit.'\* This could put a large hunk of tax free money in your pocket.

Some of these documents have slightly different names in different countries, your lawyer will be able to advise you of the correct document names for where you live.

## Social Security

Apply for Social Security immediately. This document will get you started:

<http://www.alsforums.com/forum/general-discussion-about-als-mnd/27029-applying-social-security-disability.html>

## Notification & Identification

### Directives for First Responders

As soon as you and your PCP (Primary Care Provider) deem it necessary, fill out your state's or country's version of the directives for First Responders.

These HIPAA compliant forms, once signed by your PCP, summarize important medical facts regarding your condition and details your desires such as DNR (Do Not Resuscitate) orders. It is usually printed on brightly colored paper and posted somewhere obvious.

In Colorado, my home state, it is referred to as the *Medical Orders for Scope of Treatment* (MOST)\* form, found here:

<http://coloroadvancedirectives.com/links-and-downloads/medical->

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\*Items I use regularly are marked with \*

[orders-for-scope-of-treatment-most-in-colorado/](#)

In California I found it as the *Physician Orders for Life-Sustaining Treatment* (POLST) form here:

<http://capolst.org/polst-for-healthcare-providers/forms/>

Your locale should have a similar offering.

### Medical ID Bracelets or Dog Tags

You may not always be next your Directives for First Responders, so consider some form of Medical Alert device.

I created myself a silicon 'dog tag' from RememberBand:

<https://www.reminderband.com/products/custom-dog-tag-necklace/>\*

My custom dog tag used the "6 lines of text with art" format choosing the caduceus as the art.

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Begin now to save your voice for text-to-speech apps: see [Communicating/Voice Banking](#).

You will find many more answers to 'what do I do now?' here:

<http://www.alsforums.com/forum/general-discussion-about-als-mnd/>

## **Veterans**

Veterans are twice as likely to develop ALS. If you are a Veteran and are not already in the system with an ALS diagnosis, IMMEDIATELY contact your local chapter of the Paralyzed Veterans of America (PVA) or the Disabled American Veterans (DAV), and get the process started. ALS is considered a 100% Service Connected disability.

Do NOT try to navigate the VA without assistance.

<http://www.pva.org/find-support/veterans-assistance>\*

<https://www.dav.org/membership/local-chapters/>

The Independence Fund is a service organization for Veterans which provides advocacy and some fantastic equipment programs.

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\*Items I use regularly are marked with \*

<https://www.independencefund.org/our-programs/>

For additional information on Veterans benefits:

<http://www.alsforums.com/forum/military-veterans-va/26955-guide-veterans-benefits.html>

## **ALS Organizations & Resources**

An explanation of ALS, both for your own information and to refer others to, can be seen in this series of videos, "The ABC's of ALS":

<http://thealsexpress.com/the-abcs-of-als/>

And in the webinars offered by the North East ALS Consortium's (NEALS) website:

<https://www.neals.org/for-people-with-als-caregivers/educational-webinars/>

The ALS Association provides education, grants, respite programs, referrals, and equipment loans. The local chapters set up support groups and schedule charity walks.

<http://www.alsa.org/community/chapters/>

The Muscular Dystrophy Association (MDA) is also involved with ALS and provides services similar to the ALS Association.

<https://www.mda.org/disease/amyotrophic-lateral-sclerosis>

Team Gleason also provides services, information and assistance obtaining equipment:

<http://www.teamgleason.org/>

There are also regional compassionate care providers such as the Brigance Brigade in Maryland.

<http://www.brigancebrigade.org/how-we-can-help>

Information about clinical trials and research can be found here:

<https://clinicaltrials.gov/>

## Useful Websites

There is a very active, informative and searchable web forum at

<http://www.alsforums.com/forum/>\*

ALSUntangled researches various alternate treatments. Their completed reviews can be found here:

<http://www.alsuntangled.com/completed.html>

And the pending ones here:

<http://www.alsuntangled.com/open.php>

ALS TDI (Therapy Development Institute) also has a Web forum.

<http://www.als.net/>

Patients Like Me allows you to track your progression, research how various treatments have worked for other pALS and communicate with other members.

<http://www.patientslikeme.com/>\*

ALS From Both Sides is a very valuable website managed by Diane Huberty, a former nurse specialist in Neuroscience and an ALS patient diagnosed \*\* 30 \*\* years ago. Diane's website details both her learnings as a pALS and her experience as a nurse.

<http://www.alsfrombothsides.org/>\*

Every 90 minutes has an ALS technology guide and other information.

<http://www.every90minutes.org/als-technology-guide/>

At some point you will have to consider a feeding tube, Tube Chic has information on enteral formulas, both commercial and 'home blended', and on tubes in general.

<http://tubechic.com/>

## Facebook Groups

There are many Facebook groups with more appearing frequently. Here is but a few:

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*\*Items I use regularly are marked with \**

### General interest

- ALS Patient and Caregiver tips for everyday living
- The Lighter Side Of ALS (for pals only)
- Better days with ALS
- Living with ALS ~ For PALS Only
- ALS We are in it together
- Research on Motor Neuron Disorders: PLS, HSP/SP, and ALS

### Veterans

- US Vets with ALS and Caregivers
- Veterans with ALS & their Caregivers (VACs)
- Veterans with ALS (VALs)

### Supplements, Trials & Etc.

- ALS Radicava User Group
- Freedom for medical cannabis
- Cannabis oil success stories
- Pot for PALS
- Pills for PALS

### Specific issues

- Traveling with ALS
- Adult Tube Feeding
- ALS - Equipment Exchange
- I USE A WHEELCHAIR, SO WHATS THE PROBLEM?

寿命 (life)

## Treating ALS

At the time of this writing there is no cure for ALS, and only two treatments.

ALS Worldwide has released a resource that explains the various treatments and supplements commonly used with ALS

<http://alsworldwide.org/the-als-worldwide-protocol>

## Treatments

Riluzole\* was released in 1995. It is intended to slow ALS progression, specifically to delay the need for a tracheostomy. You will see it stated that Riluzole extends survival by three months but it is more accurate to say 10%: the longer you live the greater

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*Items I use regularly are marked with \**

benefit seen. However, it is almost impossible to say what benefit you will see as we all progress differently. It is not an exaggeration to say we take it on faith. I know I do.

<https://en.wikipedia.org/wiki/Riluzole>  
[http://web.alsa.org/site/PageServer?pagename=ALSA\\_Ask\\_Dec2011](http://web.alsa.org/site/PageServer?pagename=ALSA_Ask_Dec2011)

Edaravone, or Radicut, was recently released. Used in Japan for many years to treat ALS and stroke victims, Edaravone was fast-tracked by the FDA to treat ALS. This IV (infusion) drug is effective primarily for those very early in their progression. Like Riluzole this drug can slow progression. And also like Riluzole we have to take it on faith.

<https://en.wikipedia.org/wiki/Edaravone>

There are no other treatments for ALS. Anyone who tells you otherwise is a fool or a scammer.

There are, however, many FDA approved trials currently underway, so keep watching!

<http://www.als.net/als-research/als-clinical-trials/>

There are treatments for various ALS symptoms, such as muscle cramping and Pseudobulbar Affect (PBA). Various forms of Magnesium can help with cramping, and Nuedexta is prescribed for PBA.

[https://en.wikipedia.org/wiki/Pseudobulbar\\_affect](https://en.wikipedia.org/wiki/Pseudobulbar_affect)

## Supplements

Magnesium<sup>\*</sup>, mentioned above for cramps is one of many supplements used by pALS.

Vitamin B12<sup>\*</sup>, specifically the methylcobalamin form, is recommended by ALS Worldwide to slow progression, if you are still in the early phase:

<http://alsworldwide.org/whats-new/article/about-methyl-b12>

pALS can and do spend time and money researching and trying supplements such as vitamins, minerals, herbs and other.

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*\*Items I use regularly are marked with <sup>\*</sup>*

Be aware that supplements can interfere with drugs, including Riluzole. Before starting any supplement, run it through WebMD or your pharmacist to check interactions.

<http://www.webmd.com/interaction-checker/default.htm>

There are multiple 'protocols' being used and discussed including the 'Proletariat Protocol' and the 'Deanna Protocol.' The latter has been reviewed by ALSUntangled:

<http://www.tandfonline.com/doi/full/10.3109/21678421.2013.788405>

Here is a wiki listing some of the supplements that have been tried:

[http://alstuttu.org/wiki/index.php?title=Information\\_on\\_nutritional\\_supplements\\_people\\_with\\_ALS\\_have\\_been\\_taking](http://alstuttu.org/wiki/index.php?title=Information_on_nutritional_supplements_people_with_ALS_have_been_taking)

Medical marijuana<sup>+</sup>, or cannabis, is often of interest to pALS. There is research suggesting that one or more of the cannabinoids, primarily CBD but also THC, are neuroprotective. CBD is not psychoactive. THC, the cannabinoid responsible for the 'high', has successfully been used to lessen cramps and help with sleep. More here:

<http://www.alsforums.com/forum/als-research-news/31948-cbd-thc-etc-dosage.html#post377561>

New Zealand is considering legalizing cannabis, their recent study can be read here:

<https://www.msnz.org.nz/wp-content/uploads/2018/02/Executive-Summary-Medicinal-Cannabis-Report-MSNZ-2018.pdf>

## Scams

A word of caution: As pALS we can and do easily fall victim to scammers.

A cure will be found, but we're not there yet.

In spite of this there is no end of people trying to sell a cure or treatment.

A few of the more common scams include:

- Chleation therapy

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*Items I use regularly are marked with \**

- Removing mercury-based fillings (removal can release more mercury than just leaving them alone)
- Alkaline water
- Stem cell clinics (NOT including FDA approved trials: these are a great source of hope!) Please read this: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3273527>
- Lyme disease testing/treatment, past what your neurologist offers
- At this time, the newest scam is African Herbs

If someone approaches you with a cure or treatment, research it!

Check the ALSUntangled reviews mentioned above!

Ask in the forums and Facebook groups!

Ask fellow pALS!

And most important, use common sense! It's an overused saying, but if it sounds too good to be true, it probably is.

*When a real cure or treatment is found, it won't be a secret.  
I and every pALS I know will be shouting the news as loudly as possible.*

## **Hard Decisions: Eating & Breathing**

Feeding tubes and ventilators are two of the most difficult issues that you will face. These decisions are emotional and may have huge effects on your family, but in the end they are solely yours to make. My goal here is to help you make informed decisions.

You will hear people say "No tubes, nothing artificial!" Sadly, this is too often said in ignorance.

### **Feeding Tubes & Nutrition**

When swallowing becomes difficult, you face the danger of aspirating your food. This can result in pneumonia, which can be fatal for a pALS.

A G Tube allows you to obtain nutrition, hydration and medicine without danger of aspiration.

### **Types of Feeding Tubes**

There are different types of G Tubes and different types of operations used to place them.

The operations are:

- PEG\* (Percutaneous Endoscopic Gastrostomy) done under general anesthesia. The most common type
- RIG (Radiologically Inserted Gastrostomy) done under 'twilight sleep'. Used when breathing is an issue
- PIG (per-oral image guided gastrostomy) which is least common

The various types of tubes include:

- Dangers\*, which are tubes with 12-18" of external tubing and usually an internal bolster to prevent the tube from pulling out. (which is a scary but not grave problem). These can last for years before needing replacement. Some dangers can use internal balloons instead of the solid bolster. These will eventually fail and need replacement.
- Low profile or button, which does not have the long external tube but does require an 'extension' tube for use. This type can have an internal bolster but more commonly use an internal 'balloon'. Just as the above, these balloons will eventually fail.

You may be alarmed at the thought of your G Tube balloon failing. No need to worry, they're normally checked and replaced on a regular schedule. On the rare chance it fails and gets tugged out, STILL don't worry. You won't leak like a ruptured balloon. Simply cover the exposed stoma and go visit the Emergency Room. They'll likely plug it with a Foley catheter and direct you to make an urgent appointment with your doctor. Many pALS have a spare G Tube on hand for just this possibility.

There are also J (jejunostomy) Tubes, which bypass the stomach and go to the middle of the small intestine. I have not seen these used in pALS.

Note that a G Tube does not prevent you from eating or drinking for pleasure. In fact, obtaining the bulk of your nutrition and hydration via the tube preserves your energy for pleasurable eating!

The long 'dangler' tubes can be a bit of a problem to keep from flopping around and getting snagged. It's NOT recommended to tuck the end into pants or bras for fear of tugging, although many do.

Some remedies for this include:

- A G-tube holder belt\* (search Amazon for an example)
- Medical tape
- Specialized adhesive devices such as Grip-Lok Securement

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\*Items I use regularly are marked with \*

Devices

- Hanging from a lanyard

I received my PEG roughly 2 years ago and have no regrets.

## **Enteral Food**

The food you receive through a feeding tube is generically called enteral food. There are multiple brands ranging from the Boost Nutritional Drink you find in your grocery store to formulas specific for tube feeding such as Jevity or Isosource.

These standard formulas contain many artificial ingredients which has led people to seek more natural nutrition. One option for this has been met by commercial formulas such as Liquid Hope and Real Food Blends.

Another option is to blend your own. Some pALS actually eat the same meals as their families, just thoroughly blended. This does require the use of high powered blenders such as Blendtec or Vitamix. In my experience Dietitians seem to discourage 'blend your own' as there is a greater chance of clogging.

This website will get you started if you wish to try blending:

<http://tubechic.com/>

## **It's Your Choice!**

Be aware that you have the right to refuse food at any time if you so choose. However, the G Tube is still invaluable for hydration and medicine.

IN MY OPINION getting a G Tube is a no-brainer, and forcing your caregiver (cALS) to watch you choke on water and medicine, and possibly die from pneumonia is terribly selfish. But, again, it is your choice.

## **Ventilators**

When the phrenic nerve to your diaphragm begins to lose function your breathing will begin to decline. This reduction in air exchange will first be detected by headaches upon waking and lethargy. CO2 buildup causes these symptoms and can be confirmed by a simple serum CO2 test, a less simple Arterial Blood Gas (ABG), or a sleep study.

Monitoring your rate of decline is accomplished through periodic

Pulmonary Function Tests (PFTs) which is a scary name for blowing as hard as you can into a test machine. There are multiple tests possible, some Pulmonologists follow FVC%, which measures your ability to force air out of your lungs as a percentage of what a "normal" person would blow. Others may monitor SVC, which is the quantity of air you move with normal breathing.

A BiPAP (Bi-level Positive Airway Pressure, similar to the CPAP machine used for sleep apnea) is used to remedy this issue.

Ventilators which can function as BiPAPs, such as the Phillips Trilogy 100\* are commonly prescribed when your breathing declines.

Initially the BiPAP will be used during sleep, which is when respiration is normally depressed, but eventually will be needed 24/7.

I currently use my Trilogy 24/7 but can go without for up to 2 hours.

Ventilators have a couple of odd side effects that seem to happen during sleep:

- Severe dry mouth. Biotene is commonly used for this but in my experience it's effects only last for an hour. I have found a product that last for several hours called XyliMelts\*. I get them off Amazon
- Air in stomach. If you are not expecting this, being awakened by a distended stomach can be scary. Weakened throat muscles cause you to swallow air. The answer is to sit up and burp

## **Ventilator Masks**

There are three general types of masks used with ventilators:

- A full face mask covers from above your nose to under your mouth. This seems to be the mask most commonly dispensed, but it is both the least comfortable and most claustrophobic choice. As you can well imagine, both eating and talking are a challenge with a full face mask.
- The nose mask is a smaller version of the full face. It's basically a cup that surrounds your nose. Eating and talking are possible with a nose mask. My personal opinion is that this is the best starter mask, and possibly the only one you'll need. The only issue I've had with this style is that it has rubbed

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\*Items I use regularly are marked with \*

against my nose's septum and caused a painful sore. Depending on the specific mask, you may be able to wear glasses. I use this mask occasionally.

- The nose pillow mask is the most compact mask used. As the name implies, two soft silicon 'pillows' snug up to your nostrils. As with the nose mask, this mask allows eating, speaking and, usually, wearing glasses. This mask can be difficult for a beginner as the air seems to 'jet' into your nose. Another issue is that a poor fit can create painful sores where the pillows touch your nostrils. I use this mask the majority of the time.
- Contrary to what I said above, there is 'sort of' a fourth style of mask. An all-cloth mask called the Circadience SleepWeaver masks come in both full-face and nose masks styles. I've personally not tried one, but they sound quite comfortable.

After getting used to either the nose mask or nose pillow mask, I've learned that the full face mask is no longer claustrophobic. I actually have all three styles on hand.

For about a year I lived in mild fear of nose congestion preventing me from using either of the two nose masks. This fear was unfounded as the air pressure from my vent has proven adequate to overcome any blockage.

## **Breath Stacking**

Breath stacking<sup>\*</sup> is the process of inflating your lungs to the maximum possible. Many pALS practice breath stacking to help maintain breathing for as long as possible. It can be done unassisted or with a Cough Assist machine:

<http://www.alsforums.com/forum/general-discussion-about-als-mnd/27207-breath-stacking-again.html>

## **Cough Assist**

At some point as your breathing declines you will have difficulties inhaling enough air to form a useful cough. A cough assist machine is designed to fill your lungs fully and then quickly extracts it, simulating a cough. The cough assist I have is made by Phillips:

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*\*Items I use regularly are marked with <sup>\*</sup>*

<https://www.usa.philips.com/healthcare/product/HC1098160/coughassist-t70-ventilator>

Be aware that the cough assist uses a different mask than ventilators; it uses the same mask seen on television shows when someone is 'bagged'.

Cough assists need to have the settings customized for your specific needs, just as a ventilator does. Do not let your respiratory therapist leave one without setting it and teaching you to use it. As mine did.

## **Tracheostomy**

Eventually the 'non-invasive' BiPAP will become inadequate and you will face the decision to undergo a tracheostomy and become dependent upon a full-time ventilator. This is referred to as 'invasive ventilation'. A Trilogy or similar vent will be used for this.

This is arguably the most serious, the most emotional question you will face.

You will no longer be independent: trained care must be rapidly available 24/7 to answer ventilator alarms and to suction mucus. This does not require professional help as any cALS can be trained, but will require more than one cALS to allow for sleep, shopping trips and just plain downtime.

In Japan roughly 70% of pALS become trached as it is expected by their society. Sadly, in the US this number is in the teens. You may encounter Doctors that recommend you not undergo this operation, and that is a terrible shame. Ask them to justify their opinion, weigh their words carefully, but do your own research. The decision is yours, not theirs.

This sounds dire and I will not downplay the seriousness of this decision. But know that this does not have to turn you into one of those 'suffering, bed-ridden' ALS patients you see on TV. pALS can and do remain mobile and find joy in life.

For two living examples I refer you to:

- [Steve Gleason](#)
- [Diane Huberty](#)

Diane, as mentioned earlier under Websites, is a \*30 year\* ALS survivor and has been trached since 2004. Diane's reflections on

being trached can be read here:

<http://www.alsfrombothsides.org/r-vt-safeharbor.html>

At this time my decision is to undergo the operation when it becomes necessary. I am not ready to die and I also believe a cure is coming. But I have to live long enough to see it!

This topic was recently discussed in ALSForum. The thread was started by a pALS who was facing the operation in a few weeks.

<http://www.alsforums.com/forum/people-als-pals/39112-questions-about-tracheostomy.html>

## **Panic Attacks**

I am placing this here as my panic/anxiety attacks were directly related to my declining breathing. Panic attacks are not uncommon. There are several drugs to help: I've been taking Mertazapine\*.

The best way to endure a panic attack is to remember it will end. Focus on that fact and do your best to relax. An anxiety attack is a self-feeding condition, so try to not feed that cycle. Relax.

## **Wet & Nasty Stuff**

### **Phlegm / Mucus**

This is a common problem. Some of us begin to suffer from this after we start on vents, some before. The mechanical treatment is use of a Cough Assist\*. Also useful are daily use of:

- Percussion vest
- Pineapple juice
- Papaya juice
- Alka-Seltzer (yes, really!)
- N-acetyl cystine (NAC)

### **Drooling**

As symptoms progress to Bulbar regions (swallowing, speech difficulties, etc.) excess saliva can become an issue. Some simply use a towel or cloth to catch the 'overflow' but there are treatments, including:

- Botox injections into salivary glands

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\* Items I use regularly are marked with \*

- Radiation treatments

## Bathroom Concerns

Your toileting problems will vary according to your type of onset: limb or bulbar. However, some or all of the following may be useful.

Constipation is often encountered by people on feeding tubes.

- Work with a Nutritionist/Dietitian to find the enteral formula that works best for you
- Colace\* or similar stool softeners are commonly added to daily meds
- MiraLax\* is commonly used, to good effect
- Be sure to drink adequate water, even if it means more bathroom trips
- Severe constipation can require a trip to the ER

Urgent/Spastic Bladder

- Oxybutinin Chloride\* will lessen the urgency
- Consider having a portable urinal\* handy
- Condom or Foley catheters\* for trips or for when urinals are inconvenient

When your hands begin to go, consider a bidet, such as the BioBidet BB-400\* or similar. These are also handy in the case of impacted bowels.

Actually getting on a toilet will become an issue when your legs begin to fail. Transferring from a power wheelchair (PWC) to the toilet will use the following

- A pivoting transfer disk, while you can stand with assistance
- A transfer board\* to slide from the PWC to the toilet and back
- Finally a Hoyer lift\* when you have no leg function

These also apply to getting into and out of bed.

Power wheelchairs are usually 3 to 4 inches taller than toilets, making sliding transfers difficult. Risers will fix this

- A toilet base riser\* will lift the entire toilet to the correct height
- A toilet seat riser lifts the seat, these can be portable

Grab bars\*, permanently floor or wall mounted or temporary ones bolted to the toilet seat mount, are a requirement at this point.

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\*Items I use regularly are marked with \*

沉着 (rebirth)

## Communicating

A two-way baby monitor (or, in my house the geezer monitor) is one of the easiest ways to communicate.

A fellow pALS recently reminded me of Amy Roman's communications website. As a Communications Specialist, she covers many of the topics I touch on below.

<http://amyandpals.com/>

## Alerting & Alarming

While you have functional hands the 'help I've fallen' device or similar can ensure that you can contact people and/or 911.

<http://www.lifealert.com/>

[https://www.logicmark.com/products/unmonitored/freedom-alert/\\*](https://www.logicmark.com/products/unmonitored/freedom-alert/*)

However once your hands go you'll need to find something else. This product has monitoring, fall detection and 2-way voice:

<https://www.medicalguardian.com/products>

Once both hands and voice weaken, getting the attention of your caregiver becomes an issue. There are multiple switch/alarm devices for this, but most still require an ability to move some body part.

Examples include:

- Pillow switches, activated by head
- Large strike buttons, activated by hand, arm, foot or leg
- Sip-n-puff switches controlled by mouth

Diane Huberty, mentioned previously, has a nice write up on her website:

<http://www.alsfrombothsides.org/e-call.html>

## Text-to-Speech & Eye-Gaze Computers

Text-to-speech is used on computers and cellphones to read words, sentences or pages of text aloud. Using various PC and/or cellphone apps, a user can interactively supply this text to the PC or cellphone and have it read aloud to a listener.

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*\*Items I use regularly are marked with \**

Eye-gaze computers provide text-to-speech and a rich variety of other 'hands-free' capabilities, as well as standard Windows tablet applications such as web browsing, Facebook, chat, and document creation and editing. This document was created and edited using eye-gaze. Eye-gaze computers are classified as Augmentative and Alternative Communication (AAC) devices.

Instead of the touch of a finger on a touch-screen or keyboard/mouse, eye-gaze computers use a small infrared (IR) emitter and camera to track the spot on the screen at which you're looking.

This same technology is being used by PC gamers!

## **Voice Banking**

Voice banking is the process of capturing your voice for use on a computer or other text-to-speech app. If you act while you still have an adequate speaking voice, you can capture it and use that in place of the robotic 'computer voice.' There is a fair amount of tedious 'speaking phrases' involved, so start this early.

My Modeltalker synthetic voice isn't perfect: it's a touch robotic still. But it's recognizably my voice.

Modeltalker is one group offering to capture and create your synthetic voice for \$100\*

<https://www.modeltalker.org/faq/> ■ ■

Team Gleason has arranged for FREE voice banking for pALS. See this for more information:

<http://www.teamgleason.org/wp-content/uploads/2018/01/Model-Talker-Press-Release-6.pdf>

Tobii also offers this service for \$1,500 (no, not a typo)

[https://www.tobiidynavox.com/en-US/software/partner-software/vocal\\_id/](https://www.tobiidynavox.com/en-US/software/partner-software/vocal_id/)

A few of the other capabilities provided by eye-gaze computers:

- Hands-free cellphone using either actual speech or text-to-speech\*
- Text messaging\*

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*Items I use regularly are marked with ■ \**

- TV/cable/DVD/etc. IR remote
- Simplified interfaces to:
  - Facebook
  - Email
  - Calendars
  - Music files
- \* *requires cellphone with Bluetooth*

Tobii Dynavox produces a line of eye-gaze computers as well as special hardware that enables eye-gaze on Windows PCs.

<https://www.tobiidynavox.com/en-US/products/devices/>\*

There are other vendors of eye-gaze computers but I have no knowledge of them. Sorry!

### **Text to Speech (TTS) Applications**

If you don't have an eye-gaze computer you can still use TTS applications on your laptop or PC. A few of the free TTS apps are:

- Balabolka <https://balabolka.en.softonic.com/?ex=DSK-347.0>\*
- Natural Reader <https://www.naturalreaders.com/>
- Panopreter Basic  
<http://www.panopreter.com/en/products/pb/index.php>
- Talk for Me <https://www.retconapps.com/talk-for-me/>\*

### **Google Voice**

Now that your computer can talk for you, how can you use that to place a phone call? If you have a Tobii or similar device, there is a phone app that connects to your cellphone via Bluetooth.

But for those without such apps or without a cellphone, you can use Google Voice\*.

Google Voice provides you with a new phone number in the area code of your choice and binds that number to your cell or home phone number. With it you can text, place free calls and even have voicemail.

More here

<https://support.google.com/voice/answer/115061?hl=en>

### **Telecommunications Relay Service (7-1-1)**

If you do not have a Text-to-Speech device there is a free, nationwide service that enables you to communicate through a

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\*Items I use regularly are marked with \*

Communications Assistant.

The Communications Assistant can either read your typed statements or interpret your voice and relay that to the person you're calling. You are able to hear both sides of the conversation.

The assistants who interpret your voice are specially trained to understand speech defects.

This service is also known as the 7-1-1 telephone service.

The type of relay service most commonly used by a pALS is Hearing Carry Over (HCO).

HCO is described as follows

HCO allows a person with a speech disability who can hear to make a call by typing to the Communication Assistant (CA) who reads the message to the other party. The HCO user can hear the other party's spoken responses through the phone.

HCO requires a Text Telephone (TTY) device or the download of a TTY app onto your computer or smartphone.

Information on various TTY downloads for cellphones can be found here:

<https://www.healthyhearing.com/report/50160-The-best-phone-apps-for-video-relay>

Similar to HCO is IP Relay. IP Relay uses a web-based application versus a TTY. Which means that no apps other than a Web browser is needed.

IP Relay is described as

A Web-based service for text users who are Deaf, hard of hearing, or have speech disabilities. This is a free, federally reimbursed service and not part of CRS. Text users who are Deaf, hard of hearing, or speech-disabled can initiate a relay call using a computer or wireless phone with Internet access.

More information on IP Relay service can be found here:

<https://www.fcc.gov/consumers/guides/ip-relay-service>

The IP Relay website run by Sprint which includes a registration link, can be found here:

<https://www.sprintip.com/>

The interpreted relay service is Speech-To-Speech (STS). STS is described as

A person with a speech disability talks to a communications assistant with special training in listening and understanding a variety of speech disorders. The communications assistant repeats everything, making the caller's words clear and understandable.

STS does not require any apps or downloads, only a telephone.

For more information:

<https://www.ada.gov/reachingout/telerelay.html>

<http://ddtp.cpuc.ca.gov/default1.aspx?id=1483>

A link to your US state Relay Services and other information can be found here:

<https://www.sprintrelay.com/>

## **Pointers & Placard**

There are also low-tech solutions that use a pointer, such as a laser, to select words or symbols on a placard. An example of the versatility of this method can be seen on the TV show "Speechless."

## **Amazon Alexa & Google Home**

Another thing I've recently discovered is Amazon's Alexa\* devices: the Echo, Dot or Show.

The Dot is fairly inexpensive at \$50 (or \$35 if you catch it on sale).

I've recently learned that these devices respond well to text-to-speech (e.g. Tobii computers).

The Google Home appliance has similar capabilities but I've no personal experience with it.

## **Messaging and Calling**

There are currently four separate methods of using Alexa Echos/Dots to contact someone:

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*Items I use regularly are marked with \**

### Echo Connect

This recent (available December 2017) Echo add-on will effectively turn your Echo into a speaker phone on your home phone line. This allows hands-free placing and answering of live phone calls. Unlike the other three messaging capabilities this one enables you to call 911! That's truly a big deal.

<https://www.amazon.com/Echo-Connect-requires-device-service/dp/B074TTVOYP>

### Alexa to Alexa Calling ■■

This requires a that cellphone is associated with your Amazon account. The Alexa app is installed onto your cellphone, and the phone Contacts are pulled into the App. Any contact with an Echo/Dot or the Alexa app on their cellphone can now be called.

<https://www.amazon.com/gp/help/customer/display.html?nodeId=202136190>

### AT&T Messaging \*

If you have an AT&T cellphone you can send voice messages (NOT calls) to AT&T contacts you set up in the skill.

<https://www.att.com/offers/send-messages-amazon-echo.html>

### Ask My Buddy \*

Add this 'skill' to set up a list of up to 10 contacts on the free Ask My Buddy website, and you can send voice messages (again, NOT calls) to those contacts.

[https://www.askmybuddy.net/quick\\_start.php](https://www.askmybuddy.net/quick_start.php)

## **Intercom**

There are four ways to use Alexa devices as intercoms:

### Multiple Alexa Devices and Separate Amazon Accounts \*

This first way is better for me as it calls both the Echo/Dot and the linked cellphone simultaneously. Whichever device that gets answered first gets the call.

Normally, multiple Echos/Dots in the same household are set up using the same Amazon account. But this doesn't have to be the case.

My original Echo is in my bedroom and linked to my cellphone. One of my two Dots is on the main floor (where my wife sits) linked to her

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\*Items I use regularly are marked with ■

cellphone. The second Dot is in my son's basement bedroom linked to his cellphone.

When I'm in bed I simply say "Alexa call Barbara (or Trevor)" and the appropriate Dot (and it's linked cellphone) will notify that there is an incoming call from me!

#### Multiple Alexa Devices, Shared Amazon Account\*

The second way assumes that all the household Echos/Dots are set up linked to one Amazon account and that account's single cellphone. Using this method only one specific Alexa or one specific phone contact is called.

When an Echo or Dot is originally set up, that device gets a default name, such as 'Greg's Echo.' However, the Alexa app (on your cellphone or PC) allows you to rename the devices.

I renamed 'Greg's Echo' to 'Master bedroom', and 'Barbara's Dot' to 'Living Room.'

With these new names, I can say, "Alexa call (device)."

For example from my bedroom, to call my wife downstairs, I say, "Alexa call Living Room," and only that specific device 'rings.'

The three methods of using the Alexa devices as intercoms can both be set up and used as needed.

#### Multiple Alexa Devices, Using 'Drop In'\*

The third 'intercom' feature is Drop In. Multiple Echos/Dots/Shows are set up as above, with room names. One simply says "Alexa, drop in on <room name>" and the Alexa device in <room> announces an incoming call.

#### Multiple Alexa Devices using Broadcast / Announce\*

The fourth 'intercom' feature is the Broadcast (or Announce) skill. It's one way, so it's more accurately a Public Announcement system than an intercom, but it's quite useful nonetheless.

Use is quite simple, say to any Alexa device "Alexa, Broadcast (or Announce) < whatever >" and every other linked device will repeat < whatever >.

You can have a bit of fun with this built-in skill; it has a few Easter eggs:

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\*Items I use regularly are marked with \*

Wake Up - Sound Effect: Rooster Crow

• Say: "It's time to wake up", "rise and shine"

Quiet Time - Sound Effect: Shhhh

• Say: "Quiet Down", "Everyone be quiet"

Late/Let's Go - Sound Effect: Feet running

• Say: "We're late", "Let's go"

Bedtime - Sound Effect: Twinkle Twinkle

• Say: "It's time for bed", "Time to sleep"

Goodnight - Sound Effect: Yawn

• Say: "Goodnight everyone", "Sleep tight"

Meal - Sound Effect: Dinner bell\*

• Say: "Breakfast/Lunch/Dinner's ready", "It's time to eat"

Congratulations - Sound Effect: Cheer

• Say: "Congratulations," "Way to go"

Media time - Sound Effect: Show tune

• Say: "Let's watch TV", "The movie is about to start"

Love you - Sound Effect: Playful kiss

• Say: "love you"

Very important point: Only the Echo Connect can call 911.

The Alexa devices can also:

- Play music, podcasts and radio
- Set reminders and alarms
- Read books
- Control Home Automation

My future plans include setting up Home Automation and using voice commands through the Alexa to control it.

## Home Automation

Home Automation (HA) can give you back control of:

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\*Items I use regularly are marked with \*

- Lights
- Door locks
- Thermostats
- Ceiling fans

As well as give you access to:

- Security cameras
- Motion detectors
- Leak detectors
- And much more

There is seemingly no end to the technologies used in HA, and it would be impractical to list them here. CNET, the tech website, has a beginners guide:

<https://www.cnet.com/news/smart-home-buying-guide-home-automation/>

If you've an interest in HA, you should look into Team Gleason's Home Automation initiative:

<http://www.teamgleason.org/homeautomation>

## Traveling

Yes, it's still possible. Steve Gleason does it even with a tracheostomy, but to be fair, he does have a very good support system. The complexity with depend on your degree of progression; able to walk with assistance, permanently in a PWC, and invasively ventilated (trach) are examples of different levels of difficulty in travel.

As noted earlier, there is a Facebook group for this

- Traveling with ALS

The ALS Association has multiple articles on this subject, here are a couple:

- <http://www.alsa.org/als-care/living-with-als/traveling-with-a-disability.html>
- <https://alsadotorg.wordpress.com/2017/09/21/helpful-tips-for-traveling-with-als/>

Christopher Reeves (Superman!) didn't have ALS but he was a quadriplegic with a tracheostomy, his foundation has a few tips:

<https://www.christopherreeve.org/living-with-paralysis/home-travel/traveling-with-your-wheelchair>

And finally, here is a useful website:

<https://wheelchairtravel.org/air-travel/>

If you're a fan of our US National Parks you have to read this:

<https://store.usgs.gov/access-pass>

## Comfort & Locomotion

Sitting in a wheel chair all day can get uncomfortable. Be sure to get a ROHO\* seat cushion. Medical sheepskin can keep your seat cooler in the summer and warmer in the winter. A standard towel keeps your chair back cooler.

In spite of the above most of us still get itchy. Anti Monkeybutt\* powder, liberally applied, is great for this. Gold Bond powder works well, too. Find on Amazon and some pharmacies.

When your reach starts to go, get a back scratcher.

As soon as you begin using the wheelchair full-time, please discuss taking aspirin with your doctor. DVT, deep vein thrombosis, can kill you.

Falling is a serious concern. Falling can put you into the hospital and some believe it has hastened their progression. An 'ankle foot orthotic' (AFO) will help prevent tripping from foot drop. My thoughts on falling:

<http://www.alsforums.com/forum/general-discussion-about-als-mnd/31508-pride-goeth-before-fall-cautionary-tale.html>

As your walking worsens you will likely use some or all of the following:

- Cane or walking stick\*
- Ankle Foot Orthotics (AFOs)\* <http://www.alimed.com/afo-info/>
- Hiking poles or crutches\*
- A gait belt, which allows your caregiver to assist walking
- Rollator, aka '4-wheeled walker'\*
- Scooter (note: few choose this, for most these are only useful briefly)

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\*Items I use regularly are marked with \*

- Power wheelchair (PWC) \*

臂 (strength)

## Exercise

This is an area of some contention, but the consensus is that heavy 'muscle building' exercise should be avoided. The belief (fear?) is that the normal tear down of muscle tissue generated by heavy exercise cannot be repaired.

Moderate exercise, such as resistance or isometrics, and stretching exercise, such as yoga, is preferred.

Pool exercise is excellent as the buoyant water reduces joint strain and prevents rapid movement. Your OT can recommend various exercises for the pool.

More here:

<http://alsworldwide.org/care-and-support/article/exercise-helpful-or-harmful-in-als>

## Range of Motion

Range of motion \* or ROM, is highly recommended. ROM can prevent stiffening joints and curling fingers.

More on range of motion including examples here:

[http://alsworldwide.org/assets/misc/RANGE\\_OF\\_MOTION\\_EXERCISES\\_WITH\\_PHOTOS\\_copy.pdf](http://alsworldwide.org/assets/misc/RANGE_OF_MOTION_EXERCISES_WITH_PHOTOS_copy.pdf)

## Other Adaptive Equipment

In addition to the communications, walking and toileting equipment mentioned above there is a vast array of equipment to help you cope with weakening muscles.

This ranges from eating assistance:

- Padded sleeves to make utensils easy to grip
- Bowls with lips to prevent food from scooting off
- Rocker knives to make cutting easier

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\*Items I use regularly are marked with \*

- A robotic spoon to lift food to your mouth

to bed aids:

- A "bed cane" \* that assists getting into and out of bed-ridden
- A trapeze that helps you sit up or shift
- A "foot tent" \* that keeps the pressure from bedding off your feet

to door opening:

- A key cover \* that gives a better grip
- Slip on sleeves to make doorknobs easier to turn

to writing assistance:

- An easy to grip pen \* with a finger hole

to furniture:

- A recliner that lifts you to your feet
- Bed tables
- Roll around and wall mount holders for computers

Your Occupational Therapist will literally have a catalog of equipment!

## Miscellaneous

### Acid tears \*

At some point you'll encounter these. Just like it sounds, when your eyes water it will feel like someone poured lemon juice in them. Treatment is simple: wipe them. A damp cloth does the best job, but anything helps. Your doctor has likely not heard of this issue but it is common.

### Discounts

Do NOT forget to ask about Senior/Handicapped Discounts!

In some states property tax is waived.

And for the travelers among us:

[https://www.nps.gov/planyourvisit/passes.htm#CP\\_JUMP\\_5088581](https://www.nps.gov/planyourvisit/passes.htm#CP_JUMP_5088581)

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*Items I use regularly are marked with \**

## Glossary of Terms & Acronyms

AAC	Augmentative and Alternative Communication device. A Tobii or similar device used for communication
ABG	Arterial Blood Gas. Blood test that provides many results, including CO <sub>2</sub> , O <sub>2</sub> and pH. Blood is drawn from artery
AD	Alzheimer's Disease
AFO	Ankle-Foot Orthotic. An appliance to compensate for foot drop.
ALS	Amyotrophic Lateral Sclerosis, aka Lou Gehrig's disease. The most common Motor Neuron Disease, characterized by loss of both UMNs and LMNs
ALSA	ALS Association
AVAPS	Average Volume Assured Pressure Support. Ventilator technology
BAD	Brachial Amyotrophic Diplegia, or flail arm syndrome. Refers to a lower motor neuron condition affecting just the upper extremities.
BFS	Benign Fasciculation Syndrome. NOT a Motor Neuron Disease (MND) but frequently mistaken for one by laymen
BiPAP	Bi-Level Positive Airway Pressure. A type of non-invasive ventilation which administers one pressure for inhalation and another for exhalation. Used for reducing work of breathing in ALS.
Button	Slang / generic term for feeding tube with no external tube, requires extension tube for use (see Dangler)
bvFTD	Behavioral FTD. A variant of FTD characterized by personality and behavior aberrations
cALS	Caregiver for someone with ALS
Cannabinoid	One of ~123 organic compounds found in Cannabis (marijuana) or hemp, e.g. THC, CBD, CBN, etc.
Cannabis Oil	An alcohol-based suspension of cannabinoids and terpenes extracted from either Cannabis species, high in THC. See FECO, Hemp oil
Carrier Oil	An edible oil used to dilute the resinous extract from Cannabis creating Cannabis Oil or Hemp Oil. Can be olive oil, hemp seed oil or other
CBD	Cannabidiol. The primary cannabinoid in hemp oil
CBDa	Cannabidiolic Acid. Precursor to CBD, non-psychoactive. Found in raw (unheated) cannabis
CO <sub>2</sub>	Carbon Dioxide. A gas that can buildup and cause health issues if a pALS cannot breathe effectively
Comm. Assistant	Communications Assistant. A specially trained person who facilitates communication using Telecommunications Relay Services
Cough Assist	A machine that simulates a cough to assist in removing mucus from the lungs. See Vest
CPAP	Continuous positive airway pressure. Used in sleep apnea treatment; generally not for ALS, but the masks are the same. See BiPAP

Dangler	Slang / generic term for feeding tube with long external tube. See Button
DAV	Disabled American Veterans. A service organization which assists US Veterans. See PVA
Distillate	A chemical isolation and concentration of a cannabinoid, usually CBD. Lacks other cannabinoids and any terpenes. See Entourage Effect
Edible	Cannabis compounds such as THC and/or CBD mixed into food stuffs such as cookies, brownies, gummy candies or suckers
EMG	Electromyogram. Tests muscles.
Enteral food	Liquid nutritional formula for tube feeding e.g. Boost, Isosource, Liquid Hope
Entourage Effect	The synergistic effect produced when the various cannabinoids and terpenes are used together in FECO, such as CBD moderating the psychoactive effects of THC
FALS	Familial (hereditary) ALS
FECO	Full Extract Cannabis Oil. Another term for Cannabis Oil. See RSO, Cannabis Oil
FTD	Frontotemporal Dementia
FVC	Forced vital capacity. This is one of the measurements made with pfts.
G-tube	Gastrostomy tube. A feeding tube inserted in the stomach.
GJ-tube	As the name implies, a combination of a G- and a J-tube.
HCO	Hearing Carry Over, a type of Telecommunications Relay Service used by people who cannot speak but can hear
Hemp	A variety of Cannabis sativa bred to 1) contain little THC and high CBD for medicinal use, or 2) industrial uses, e.g. Paper, rope, cooking oil etc.
Hemp oil	A suspension of cannabinoids and terpenes extracted from the hemp plant, very low in THC but high in CBD. See Cannabis Oil
Hemp SEED Oil	Edible oil pressed from the seeds of a Cannabis plant. Contains NO cannabinoids or terpenes, but may be used as a Carrier Oil. Compare to olive or canola cooking oil
HME	Humidifier Moisture Exchange. A humidification method used in Ventilators, less efficient than a heated chamber
Hybrid	A genetic combination of Cannabis sativa and Cannabis indica, bred to combine or moderate the effects of the two species
IM	Intra Muscular. An injection into a muscle
Indica	Cannabis indica. A species of cannabis used for medical marijuana, allegedly more sedating than sativa
IP Relay	A type of Telecommunications Relay Service using a website for text input
IV	Intra Venous. An injection into a vein
J-tube	Jejunostomy Tube. A feeding tube inserted in the jejunum.
LMN	Lower Motor Neuron. Refers to nerve cells in the brain stem and spinal cord. Loss of these neurons leads to muscle weakness and atrophy. See UMN
MDA	Muscular Dystrophy Association
MIC-KEY	Brand name of a button-style G-Tube

MMN	Multi Focal Motor Neuron Nephropathy
MND	Motor Neuron Disease. Refers to a group of conditions characterized by loss of the nerves that control skeletal muscles, e.g. ALS, pba, etc.
MRI	Magnetic Resonance Imaging
NCS	Nerve Conduction Study. Tests nerves.
NCV	Nerve Conduction Velocity. Basically the same thing as ncs.
NIV	Non Invasive Ventilation. Use of a vent via nose and/or mouth mask. Does not use Tracheostomy
NP-tube	Nasopharyngeal feeding tube. A temporary feeding tube routed through the nose and down the throat to the stomach
NPO	nil per os. Latin for nothing by mouth (i.e. No food or drink) . See PO
O2	Oxygen. A gas necessary for life but not to be administered to pALS without adequate ventilation. See Ventilator
OT	Occupational therapy or occupational therapist
pALS	Person (or people) living with ALS
PBA	Psuedobulbar affect. Inappropriate excessive laughter/ crying. Often can be helped by nuedexta
PBP	Progressive Bulbar Palsy
PCP	Primary care provider. Generally this would be an internist, family or general physician, or family or adult nurse practitioner or physician assistant.
PEG	Percutaneous endoscopic gastrostomy. A method of inserting a G-tube using an endoscope under full anesthesia.
PFT	Pulmonary Function Test
PIG	Per-Oral Image Guided gastrostomy. A hybrid method of inserting a G-tube. Least common method.
PLS	Primary lateral sclerosis. A disorder characterized by degeneration of only upper motor neurons.
PMA	Progressive muscle atrophy. A disorder characterized by degeneration of only lower motor neurons.
PO	Per os. Latin for by mouth. See NPO
PPA	Primary Progressive Aphasia. A variant of FTD which degrades the speech and communications part of the brain
PT	Physical therapy or physical therapist
PVA	Paralyzed Veterans of America. A service organization which assists US Veterans. See DAV
PWC	Power Wheelchair
RD	Registered Dietitian
RIG	Radiologically Inserted Gastrostomy. A method of inserting a G-tube using interventional radiology with minimal anesthesia.

ROM	Range Of Motion
RSO	Rick Simpson's Oil aka Phoenix Tears. The original FECO, used a toxic chemical for the extraction process
RT	Respiratory therapy or respiratory therapist
SALS	Sporadic (non-hereditary) ALS. The most common type of ALS
Sativa	Cannabis sativa. A species of cannabis used for medical marijuana, allegedly more stimulating than indica
SCI	Spinal Cord Injury
Serum CO2	Blood test that provides CO2 content in blood. Blood is drawn from vein
SLP	Speech and language pathologist (speech therapist)
SMA	Spinobulbar Muscular Atrophy, Also Known As Kennedy Disease.
STS	Speech-To-Speech, a type of Telecommunications Relay Service used by people with speech defects
SVC	Slow Vital Capacity. Another pft measuring quantity of air in a normal inhalation / exhalation
Terpene	One of ~200 organic compounds found in cannabis, and other plants, different from cannabinoids. Source of essential oils and turpentine.
THC	Tetrahydrocannabinol the physiologically active component in cannabis, and one of the primary cannabinoids.
THCa	Tetrahydrocannabinolic Acid. Precursor to THC, non-psychoactive. Found in raw (unheated) cannabis
Tincture	An oil-based suspension of cannabinoids and terpenes extracted from either Cannabis species, high in THC. See FECO, Hemp oil
TPN	Total parenteral nutrition is the feeding of a person intravenously, bypassing the usual process of eating and digestion
Trilogy	Brand of Ventilator
TRS	Telecommunications Relay Service . Free, nationwide service that allows people with hearing or speech disabilities to communicate over a telephone or a website with the assistance of a specially trained Communications Assistant
TTY	Text Telephone, an application or device that relays typed text to a Communications Assistant for Telecommunications Relay Services
Tubie	Slang for person with feeding tube
UMN	Upper motor neuron. Refers to nerve cells in the motor cortex and lateral corticospinal tracts of the brain. Loss of these neurons leads to spasticity and poor coordination. See LMN
Ventilator	aka Vent. A device used to provide air when breathing is impaired. See CPAP, BiPAP and Trilogy
Vest	Aka Percussion Vest, Oscillation Vest. An air powered vest used to loosen mucus in the lungs. Often used in sequence with Cough Assist
VSED	Voluntary Stop Eating and Drinking. An acronym for choosing to starve to death

VSO	Veterans' Server Officer. Represents, assists and advises veterans With VA issues. See DAV, PVA
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