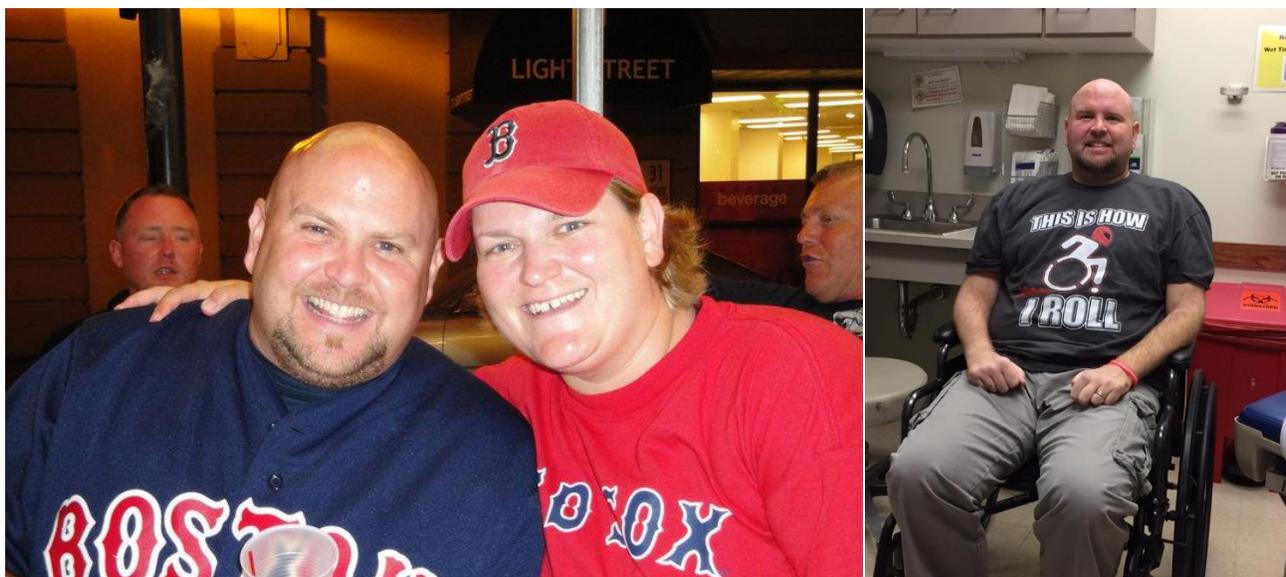


A Guide to **Living** with ALS

Thoughts from Jason Clement, an ALS Patient

Tenth Edition, May 2019



Acknowledgment

First and foremost, I would like to thank my wife, Deborah. You are my rock that I lean on every day, both literally and figuratively, for strength. I would also like to thank my family and friends. You have all been amazing! Deborah and I could never make it through without your continuous outpouring of love, support and encouragement. I would like to acknowledge the Virginia Commonwealth University (VCU) Neuromuscular and ALS Clinic team. In addition to being a great Medical Team, you are like an extended family, which means a lot to Deborah and I. I would like to thank the local chapters of the ALS Association and the Muscular Dystrophy Association. You have welcomed us into your families and supported us on our journey. Last, but certainly not least, I would like to thank my fellow ALS patients both in the area and around the world. Your sharing of your experience with me both inspired this guide and made it more meaningful. Thank you all for your continued love and support!

Introduction

In the fall of 2014, I was happy and healthy without a care in the world. Sure, maybe I was carrying an extra 30lbs in belly fat, and I probably drank more than I should have, but I felt 'healthy'. I was active, playing volleyball, golf and squash as much as possible. I had no idea that a year later, I would have played my last match of each.

In the spring of 2015, I started noticing occasional slurred words and some right hand weakness. That July, on my 44th birthday, I was diagnosed with ALS. After the initial denial, and a second round of tests and consultation at the VCU Neuromuscular and ALS Clinic, it was official, I was dealing with ALS.

I quickly found a support group for my wife and I to attend monthly, and reached out to the local ALS Association Chapter. I eventually learned that the MDA (Muscular Dystrophy Association) actively supports ALS patients as well. While I found all of these to be helpful in their own way, I still felt that new challenges were coming up at least weekly that my wife and I had to figure out for ourselves. Some were small, like button help, but others were more serious, like when is the right time to file for Social Security Disability benefits? For some of the questions that arose I was able to pick the brains of my fellow pALS (Patients with ALS), or ask my occupational therapist, but for many of the questions, we were left to figure out for ourselves, by trial and error.

As I began figuring things out for myself, I started thinking about how other pALS and cALS (caregivers of ALS patients) might find some of this to be helpful. I began tracking my 'shortcuts' and 'lessons learned' in a spreadsheet, without any real plan on how to share it. Once I 'retired', I had some extra time on my hands, so I decided to expand on the spreadsheet and add some context to each suggestion, which resulted in this eventual format.

I don't proclaim to be any kind of expert, or pretend to know it all. My intent is to simply share my experiences with other pALS and cALS in the hope that they are helped in some way. Since ALS symptoms are always evolving, our adaptations have to continue to evolve too. So, I anticipate that this guide will continue to grow over time. In fact, because every ALS patient has unique symptoms and experiences, I encourage pALS and cALS to share their experiences with me, so that I can include them in future updates to the guide.

I have intentionally steered clear of offering any medical advice here. Each ALS patient has unique symptoms and challenges. What may work well for one patient, could very well be detrimental for another. All medical treatments, even something as simple as a vitamin or a supplement, need to be discussed and decided upon with your treating physician. I hope you find this information helpful, and I look forward to hearing from you. Please share your feedback on the Comments section on our website, www.jasonclementalsfund.com/bookcomments

If you are a patient recently diagnosed with ALS, please don't think that your life is over. Instead, live life to the fullest! Since I have been diagnosed, I have been lucky enough to visit; Hawaii, Fenway Park, Nationals Park, Las Vegas, Atlantic City, Camden Yards, New York City, Citi Field, Citizens Bank Park, Yankee Stadium and PNC Park. More importantly, I have been fortunate to meet a ton of genuine, caring, generous and inspiring people that I otherwise would not have had the opportunity to meet. I plan to continue traveling and meeting new people for as long as possible.

In May of 2018, we traveled to New York City for an ALS Fundraiser benefiting Project Main Street and Team Gleason, both of whom have helped us along our journey through ALS. While everyone from both organizations was spectacular, my highlight was meeting Steve Gleason. It's not often you get to meet one of your heroes and less often that they surpass your expectations! Steve could not have been more personable, humble and welcoming!



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Chapter One - Around the House

Some of the first things to become problematic are the seemingly mundane things we take for granted every day, like writing and tying your shoes. Some of my suggestions are below, but if you encounter an issue not covered here, let Google or Amazon be your friend. I find that many of the 'arthritis aids' are also helpful to ALS patients. Your occupational therapist should have samples of many of these items for you to try, and may have additional tips.

Writing

One of the first things to try when writing becomes an issue is a thicker pen. If that doesn't work, try one of the many grips or adapters available. If/when writing becomes too difficult; consult an Attorney to execute a Power of Attorney letter. While you are there, consider drawing up a Will and an Advanced Medical Directive if you have not already done so.

Utensils

The biggest issue with standard utensils is that they are skinny and become difficult to hold on to. Getting utensils with built up grips makes them much easier to use. Good Grips brand is one option, but there are many brands available. There are also grips that attach to standard utensils.



Plates/Bowls

Sometimes scooping food from a plate or a bowl can be a problem, with food spilling over the edge. There are several plate/bowl options available with non-skid bottoms and an overhanging lip to scoop food against.



Straws / Cups

When lifting a typical cup or glass gives you trouble, consider using a straw. Sometimes a typical straw can be difficult, so look at options like the Bubba straw which is a bit wider and easier to drink from. Another option is trying one of the specialty cups available. I have found that a 16 oz. Tervis mug with, handle, lid and straw works best for me, almost like an adult sippy cup. Definitely stick with plastic, it is lightweight and more durable. Whichever you choose, buy several so you can have one available when one or more are in the dishwasher.



Scissors

Trust me, you use scissors more often than you think you do. When regular scissors become a problem, get a pair of loop scissors.



Dressing

Buttons will drive you nuts sooner or later. Invest in a button hook to reduce aggravation. When zippers become an issue, loop a thin ponytail holder through the zipper to give you a hoop to slide your finger into.



Tommy Hilfiger has just launched a line of adaptive clothing that some folks may find helpful <http://usa.tommy.com/en/tommy-adaptive>

Access

If turning a house key becomes an issue, install a keypad lock. This also allows you to enter specific codes for any caregivers helping out. And if you part ways with them, you don't have to worry about getting a key back. Simply remove their code. If doorknobs are troublesome, install lever handles. Both are available at your local area hardware store.



Socks

Avoid walking around in stocking feet. It is a major slipping hazard. If you must, then invest in socks with grip on the soles.



Shoes

Your shoe needs will change over time, depending on your disease progression. My first trouble was with tying shoelaces. I wasn't ready to take the leap to velcro closures. That left options like slip-on shoes, and my preference, athletic shoes (sneakers) with elastic laces. Replacing standard shoelaces with elastic laces lets you slip your shoes on and off without untying them. That worked for me for over a year, but as my legs grew weaker, I found my sneakers felt very heavy. There are some lightweight sneakers available, but I never found a pair that worked for me. Some had too much grip, making it tough to slide, some had too little grip. I found myself wearing slippers most of the time. But, they offer little support and tend to make my feet sweat, which caused the slippers to smell bad. I was ordering new pairs every couple of weeks. This clearly wasn't a long term solution.

We continued our search for a better shoe, when my wife suggested trying Crocs. I was reluctant, but eventually gave them a try. I never thought that I would own a pair of Crocs, but I have found that they are lightweight, easy to put on and take off, and the slip resistant model (Bistro) makes transfers much easier than slippers. I would definitely recommend giving them a try.



Contacts/Glasses

If your fingers are making contact lenses a problem, consider Lasik surgery as an alternative to wearing glasses full time. My local surgeon gave me a price break, understanding why I was having the surgery. Not dealing with glasses or contacts has been a great relief.

Light Switches

If you have finger dexterity issues, turning on a lamp can become very difficult. One solution is to buy a touch lamp, which doesn't require anything beyond a simple touch to turn it on and off. The other solution is buying a remote system that you can connect up to three lamps, or other electronic devices to. Available at your local big box store, the kit includes three plugs and one remote that turns the connected devices on/off with the simple push of a button.



One Word, Snuggie

I used to be warm all the time, but ever since I caught this stupid ALS bug, I am constantly chilly. Since my wife doesn't let me turn the temperature in the house up, I have to rely on a blanket to keep me warm. The main issues with using a blanket are keeping it in place, and keeping my arms warm, but my hands free to operate my power chair. It was a battle that I was perpetually losing. My apologies to the Snuggie Corporation for mocking you for so long!

Small Heater

If you want to avoid fighting with your spouse over the thermostat setting, keep blankets handy, and order a small, portable heater. I find that this is particularly helpful in the bathroom. I found this one on Amazon, it works great and was relatively inexpensive.

https://www.amazon.com/gp/product/B07FZR4KCJ/ref=ppx_yo_dt_b_asin_title_o07_s00?ie=UTF8&psc=1

Compression Socks

If and when you are in a wheelchair, you will likely suffer from edema (swelling) of the ankles. It's likely that your medical team will recommend compression stockings to help alleviate the swelling. There are a ton of options available. Unfortunately, most are very difficult to put on, so they will end up sitting in a drawer, not helping you. Do yourself and your caregivers a big favor and invest in a few pair of zippered compression socks. They are relatively easy to put on and take off. Most importantly, they are very effective at reducing edema. I suggest the closed toe option. They are available on Amazon.com, for example;

https://www.amazon.com/gp/product/B07B1RZGM8/ref=oh_aui_bia_detailpage_o02_s00?ie=UTF8&th=1

Television Controls

When finger dexterity problems arise, using a standard TV remote can become difficult, if not downright impossible. Thankfully, there are multiple solutions available. Many cable and satellite providers have apps available for your phone or tablet that will let control your TV. Depending on your capabilities, you may need your ingenuity to partner your eye gaze or Amazon Echo devices with the app to meet your individual needs. Some power wheelchairs (PerMobil) also have infrared capability, which means that they can be programmed so that you can use your joystick to operate your television. This has been a great help for me.



Chapter Two – Equipment

Just a reminder, I have no medical training, I am simply sharing my experience with you so that you may benefit. Please discuss the use of any of the equipment described below with your medical team to ensure that you are choosing options that meet your individual needs, and more importantly, are safe for you.

Neck Support

If there are times that you could use a little neck support (in the lift, in the car, while napping, etc.), but aren't ready to commit to a traditional neck brace, consider a travel pillow. I would recommend going to a brick and mortar store, so that you can try on several options to see which one works best for you. I found a very comfortable one at my local Target store, and bought another on Amazon. If you like it and use it often, purchase a second one so that you can wash one and still have one to wear.



Transfer Sheet

To assist with getting in and out of bed, as well as positioning, I would recommend getting a quality transfer sheet. Make sure to purchase one with handles to make life easier on your caregivers. This has also proved invaluable for transfers when EMS has responded a few times. There are many varieties available online.



Mattress Assistance

If you are having trouble with your mattress sliding when you are getting into or out of bed, I have a solution. Measure your mattress dimensions, and purchase a non-slip rug pad and place it between the mattress and box spring. These are relatively affordable and available at Home Depot, Lowe's and on Amazon.com.

Lift Chair

If getting up from a seated position is difficult, look at buying a power recliner with a lift option to help you stand. There are many options. I have found recliners with independent back recline and foot elevation controls allow me to recline most comfortably. Some insurers will assist with covering the cost.



Pivot Disc

This is something that I wish I had known about earlier, it definitely could have prevented a few EMS calls, and at least one fall. If you begin having trouble with transfers because you just can't lift your feet well enough, or like me, one of your ankles wants to roll, consider a Pivot Disc. I now use this for transfers to and from my wheelchair to my shower chair and to and from my wheelchair to and from the commode. To reduce slipping of the Pivot Disc, I would recommend placing a piece of non-skid carpet pad under the Disc (pictured below). It has made transfers much easier and safer, for both myself and my caregivers. Remember, with all equipment, please check with your Care Team to confirm that this is safe for you, and to get proper instruction on safe use.



Hospital Bed

If your breathing numbers (FVC) are diminishing, it's likely that at some point, you will be unable to sleep lying flat on your back. To help you get enough oxygen while you sleep, you will need to elevate your head. Stacking pillows may work for a while, but you should at least consider getting a hospital bed. Don't wait until it becomes an urgent need. I waited too long and ended up in the ER twice in three days due to low oxygen saturation. Please learn from my mistake, and arrange for a hospital bed early. To make things easier for your caregiver, be sure to get an electric bed instead of a crank bed. Check with your local MDA and ALS Association chapter loan closets, chances are that they will have one to loan to you. I would also suggest that you purchase a gel overlay to reduce the possibility of developing bed sores.

Home Lifts

When transfers become difficult, there are a variety of different home lift systems available. Do your research to determine which is best for you, your home and your caregivers. Check with your local MDA and ALS Association chapters for their input. The most important advice that I can offer is to begin the process earlier than you think you need to. I would count on ten to twelve weeks of time between the start of the process to delivery of your lift. If you are going with a ceiling or track lift, add a few more weeks for installation. If you wait too long to initiate the process, you are risking injury to you and your caregivers. We have used the Rifton Tram, which has its pluses and minuses. It can be operated by one caregiver, but depending upon your core muscle strength, you may need two caregivers to get you into proper position. It doesn't have neck support, which could be a problem when your neck muscles weaken.



I have no experience with the most commonly used home lift, the Hoyer lift. I have heard mixed reviews from fellow pALS. If you are considering getting a Hoyer lift, I would definitely suggest checking with your local MDA and ALS Association chapters to see if they have one available for loan. At minimum, you will want to try it out before making the considerable investment. The other important piece of advice I can offer is to opt for the power version instead of the older pump models, unless you want to give your caregivers a considerable workout every time you have to use the lift.

We ultimately chose to make a considerable investment in a Sequoia Four Post Lift System to make bed transfers safer and easier. The things that made us choose this option versus others are; no home modifications needed, one caregiver operation, two hour install by manufacturer, two-way adjustability allows for perfect placement in bed every time. This has drastically improved the bedtime and morning routines. One of the most important things to do as part of the purchase is to be properly fitted for a sling to ensure that the transfer is as comfortable as possible.



Cough Assist Machine

If your care team prescribes a Cough Assist machine, use it! The misconception that I had is that the cough assist machine should be prompting a cough each time I used it. So, I was getting frustrated with it, feeling like I was failing each time I used it. I gave up on it and put it in the closet for months. After my Respiratory therapist explained that it's all about getting air movement and loosening up things for eventual coughing up phlegm. Since I have been using it more, I am getting up phlegm throughout the day. I sleep better, without coughing all night.

Consider Investing in a Generator

If you become reliant on numerous electronics, like I have, the thought of a power outage is terrifying. At this time, I rely on my BiPAP for nighttime breathing, my lift to transfer in and out of bed and my hospital bed for getting into a comfortable sleeping position. So a few months ago my wife and I started discussing getting a generator. We started discussing the relatively small and inexpensive gasoline powered options. We live in an area with limited power outages, and this probably would have been sufficient. But, in the event of a big snowstorm, resulting in a prolonged outage, I just didn't want to have my wife worrying about getting gasoline and continually having to refuel the generator. She has enough on her plate already. Since we already had a natural gas line feeding our fireplace, we decided to install a natural gas powered whole home standby generator. In the event of an outage, we have to do nothing. The system senses the outage and the generator fires up within thirty seconds. It will remain on until it senses a power feed coming in from the grid. It was not cheap, but we received a few quotes and they were actually lower than I expected. Now we have one less worry, and we have added equity to our home. Before making any decisions, do your homework and consult with a professional, who can make recommendations based on your individual needs and budget.

Chapter Three - Getting Around

Another important thing to consider is how to get around safely, from disease onset when balance issues start to later when disease progression has you in a wheelchair.

Flooring

One of the most common tripping hazards is transition from one material to another. Moving from hardwood floors to carpet or vice versa can be dangerous as you lose your stability. As much as possible, try to minimize transitions in your home. Personally I have found hardwood or laminate flooring is the best, with carpet being the most problematic. Eliminate area rugs if at all possible.

Gravel

Avoid gravel at all cost, it is your enemy. No matter how level it looks, it will be unstable under your feet and will be a fall hazard. Trust me on this one, I learned the hard way.

Rollators

If you still have good leg strength but you are feeling a bit unsteady on your feet, a Rollator (rolling walker) may be a good option to keep you walking. Many options are available at your local home health store. Most have a built-in seat, which comes in handy when you need a rest. Find the one that's most comfortable for you.



Single Story Living

Something to consider soon after your diagnosis is whether your current residence is going to be suitable as your disease progresses. If you have tons of stairs and narrow hallways, that answer is likely 'No'. I suggest you start looking for your next place immediately, so you don't get in a bind and have to settle down the road. Personally, we were looking for a single story ranch, but when we weren't able to find that in our budget, we found a two story townhouse with a first floor master bedroom and bathroom. I have everything I need on the first floor, and have no need to head upstairs.

Stair Lifts

Stairs are the enemy of ALS patients. I recommend avoiding them at all cost. But, if single story living is not an option for you, start researching stair lift options early on. Read reviews, get several estimates and choose the contractor that best meets your needs and budget.



Scooters / Power Chairs

Scooters or lightweight power chairs are good for short term use, perhaps to get around the house, your property, the neighborhood, light shopping etc. But they are not designed for long-term use or comfort. So, if you can borrow one or get a used one at an affordable price, then go for it, keeping in mind that you will be responsible for the cost of any required maintenance. I would caution against spending a lot of money on one, or relying on it for long-term use. As soon as you see that there will be a future need for a power chair, get the ball rolling. Unfortunately, it can take 3-6 months to get a custom power chair requested, fitted, designed, approved by insurance, constructed and finally delivered. That is why getting as early a start as possible is so critical.

Team Gleason has created a short and sweet informational resource for people with ALS who are in the process of acquiring a power wheelchair, and you can download it here:

<http://www.teamgleason.org/wheelchair-guide/#wpcf7-f2687-p2652-o1>

The guide covers many topics such as:

How to start the process of getting a power wheelchair?

What factors should someone with ALS consider when choosing a chair?

What technologies are proprietary to the various manufacturers?

Alternative drive controls (how can I drive my chair with my head/pinky finger/toenail??)

How can someone apply for Team Gleason's grants for features not covered by Medicare/Insurance?

Use Your Head.....Literally

If you get to the point where your hand dexterity is impacting your ability to control your power wheelchair, there are options for you to retain the ability to control your chair by yourself. I have been pleased with my Switch-It head array, which lets me control my chair with subtle movements of my head. I had been struggling with my left hand for months. I was happy to regain some independence. While driving takes some time and practice to get down, I was immediately able to master the seating adjustments, which was awesome! I loved regaining the ability to shift my position without asking for help. I know my caregivers love that too.

Chair Accessories

If you have a power wheelchair, you will likely be spending a lot of time in it, so be sure to customize it to meet your needs. Don't be afraid to ask your wheelchair provider what may be available to meet your individual needs. The accessories that I customized on my chair are; a drink holder that can be positioned for easy access, an iPhone holder that mounts to my drink holder, a USB port to charge my phone and a hand horn that helps to keep the fingers on my right hand from curling up. The most important feature that I opted for on my chair is the optional seat raise. It allows me to raise my seat up to fourteen inches. This allows me to raise to eye level to have conversations, instead of constantly craning and straining my neck. Most insurers will not cover this option; I strongly encourage you to splurge for it if possible. Or you can get assistance from Team Gleason www.teamgleason.org/permobil-press-release/ I also suggest that you get a spare seat cushion. This allows you to wash your seat cushion whenever necessary, without being displaced from your chair while it dries.



Handicapped Placards and Plates

As soon as you feel that walking is a bit more taxing, you will want to initiate the process to secure a handicapped placard or license plate to allow you access to preferred parking. The process is pretty simple, obtain a letter from your doctor with your diagnosis and fill out a form and mail to your local DMV. If you are still driving or riding in various vehicles, the placard will work best to transfer between vehicles. But, if you are using a specialty equipped van full time, it is definitely more convenient to get the permanent license plates. While the process is simple, it could take a few weeks, so plan ahead.

Ramps

Most people picture the large, permanent wooden ramps your grandparents may have had. If you want that, go for it! Find a contractor to follow ADA guidelines and have it built. But, I would recommend looking at aluminum ramps first. They are lightweight, portable, available in a variety of sizes, and very affordable. We have something called a 'suitcase' ramp, which folds for easy storage. Some providers will rent, or even rent to own. They also make rubber threshold ramps which are great for eliminating the tough transitions between driveway and garage.

<http://www.amramp.com>



Accessible Vehicles

The most common vehicles that are modified to be wheelchair accessible are minivans. Warning, they are a lot more expensive than you might expect. Start saving, and shopping around well before you need one. There are several levels of vehicle, from fully manual to fully automated. Take the time to do your research to get the best fit for your needs and your budget. I would also highly recommend an EZ Lock system to secure your chair in the vehicle for traveling. Not only will it save your caregivers a ton of time and effort, it will also allow you to feel a lot more secure. I have recently learned that manufacturers of power chairs and accessible vehicles don't necessarily communicate very well. I learned this when I tried rolling into my van in my new power wheelchair, crashing my head into the door frame. Learn from my pain and recline your chair for van entry to avoid headaches!



After twenty months with my side entry van, my hand dexterity deteriorated to the point that I could not get in/out of the van. I now have a head array for driving, which I love, but the side entry van was very difficult to maneuver in and out of with the tight turns required. We now bought a rear entry van that is awesome. I'm able to pull straight in and back straight out. It makes me enjoy going out again! In hindsight, I wish we knew about the rear entry option from the get go. You may be tempted to save a few dollars by purchasing a van via Craigslist or through another private sale option. I would advise against this. I would suggest that you find a reputable dealer and rely on their experience and expertise to get you matched with the right equipment for you. While it may cost you a bit more upfront, it will be worth it in the long run. I highly recommend MobilityWorks. They have an experienced team and a vast inventory to find you the right fit for your individual needs and budget. You can check them out online at <https://www.mobilityworks.com/>

Chapter Four - Safety

Much of this guide is geared toward making daily living safer and easier, but there are few things that you can do specifically to prepare in the event of a fall or other emergency.

Contact Your Local Fire Department

Stop in to introduce yourself to the local firehouse or call the non-emergency fire department and let them know of your diagnosis. Have them attach your profile to your home phone/address and any cellphone you may use. If in the future you call 911 and cannot articulate your issue, they will have your diagnosis on file and won't mistake your call for a prank. Also, if you have a keypad lock you may want to give them your code so they don't have to break down your door to help you.

Emergency Beacon

Admit it, we have all joked about the 'I've fallen and I can't get up!' commercial, unfortunately now this could be you. If you plan on being home alone at all, it is wise to invest in a wearable beacon with two-way communication capability. If you already have a home alarm system, it should be an inexpensive or free add-on to get a beacon to wear as a necklace or bracelet around the house. If not, there are several companies that offer this as a standalone service. An Apple watch is another great, albeit more expensive, option for folks who may need to have an easy way to call for help even outside of the home.



Safety Trumps Pride

As much as you want to maintain your independence as long as possible, be realistic and ask for help as soon as you feel unsteady. My pride in not wanting to ask for help on the stairs cost me a trip to the ER and four staples in my head. And I was lucky I wasn't hurt more severely. Be smarter than I was.

Chapter Five- Eating/Drinking

Unfortunately, at some point, ALS may impact your ability to eat and drink normally. But, that doesn't mean you have to give up easily. There are plenty of things you can do for yourself to extend your eating and drinking time.

Small Bites

It may seem like a simple thing, but as you have less muscle strength in your tongue, moving food around in your mouth becomes difficult. Avoid issues by simply taking smaller bites.

No Talking

For a lifetime you never had to think about chewing and swallowing, so you could multi-task and even hold a conversation while eating. Now, it's more important to pay closer attention while eating to avoid choking. If someone asks you a question, finish chewing and swallowing before replying.

Eliminate Problem Foods

Everyone is different, so you will have to discover on your own what foods tend to make you cough/choke. For me, the first foods that I noticed causing repeated coughing fits were tortilla chips and bacon. I simply don't eat them anymore, problem solved! I later found that soup was a problem, because of the mix of liquid and solids. I now avoid mixing consistencies as well.

Eating Out

First and foremost, don't stop eating out. You and your spouse/significant other need to get out and keep living life. Restaurants are more than willing to accommodate you. Bring your own utensils, your own cup, or your own plate, whatever makes eating easier for you. You can also ask them to cut up your meal into bite sized pieces. I have never been turned down.

Thickening Agents

Some folks will encounter issues swallowing thin liquids such as water and juice. There are several thickening agents available online or at your local home health store. Some are better than others, sample them until you find one you like. If you struggle taking my medicine with water, consider putting pills in applesauce or yogurt the little bit of thickness helps get the pills down. Consult your care team.

Meal Planning

If you find that you are coughing more frequently during your dinnertime meal, it may be due to fatigue. You may consider moving up your dinnertime, but this isn't your only option. When I started noticing that I was coughing more during dinner than during breakfast or lunch, I started calorie loading during the earlier meals. Eating a heartier breakfast and lunch allows me to eat a more simplified dinner, drastically reducing my coughing episodes.

Food Ideas

Just because specific foods give you trouble, doesn't mean that you have to go immediately to a liquid diet. You may be fine with some easier to chew items. Below are some options that I have been able to continue eating, without issue;

Breakfast

Eggs, scrambled, or in an omelet

Biscuits and sausage gravy (my favorite breakfast)

Grits

Oatmeal

Yogurt

Lunch/Dinner

Turkey & Cheese wrap (I find that soft tortilla wraps are easier than bread)

Cheese tortellini with Alfredo sauce

Various traditional pasta dishes (Lasagna, manicotti, stuffed shells, etc.)

Enchiladas (chicken, beef, cheese)

Pulled pork or chicken BBQ

Rice A Roni, with or without ground chicken, turkey or beef

Chicken salad, Tuna salad, Egg salad (in a soft tortilla wrap)

Mashed potatoes (Bob Evans single serve are convenient)

Macaroni & cheese (Bob Evans single serve are convenient)

Pudding (so many flavors to choose from)

*For folks with excessive phlegm, be cautious with dairy products

Monitor Your Weight

When eating becomes a chore, some folks will reduce their intake, maybe without even realizing it. It's important to monitor your weight and consult with your doctor and/or nutritionist if you begin losing weight. As soon as you get a wheelchair, get it weighed, so that down the road, if you are unable to get out of the chair, you can still monitor your weight by being weighed in the chair, and then subtracting the previously reported chair weight.

Feeding Tube

One of the misconceptions of a feeding tube is that you can't eat normally once you have a feeding tube. That is not the case at all. You can continue to eat and drink normally as long as you can continue to swallow safely. Often a feeding tube is placed as a means to supply supplemental calories and/or liquids. Having a feeding tube implanted earlier while your reclined breathing is strong can reduce the risks that arise once your breathing ability declines. If you decide that a feeding tube is right for you, the first two months you will likely have a long tube. After the first few days, it's not painful, it's just annoying. Once the site heals from the surgery, hopefully you are able to switch out the long tubing for a 'button' that sits close to the skin. One of my fellow pALS turned me on to Sensi-Care Perineal/Skin Cleanser for daily cleaning of the button. I would definitely recommend it. It is available on Amazon.com.



Treat Yourself

When you are first diagnosed, hopefully before your swallowing is affected, treat yourself to your favorite foods. Don't worry about your waistline, your cholesterol, or anything else besides enjoying your favorite foods as long as you can. I consider myself very lucky that I am still able to eat three meals a day, 3 ½ years post diagnosis. But my diet has been modified to reduce choking hazards. What I wouldn't give to be able to eat a Filet Mignon, a bacon cheeseburger, chicken wings, nachos, etc. Trust me, you will be thankful later!

Chapter Six - Bathroom Stuff

I don't know about you, but when I was diagnosed, one of my first fears was dealing with bathroom issues as disease progresses. I have learned that bathroom issues may be an inconvenience, but they are far from being the worst part of this disease. Here are some things I've learned that make life easier on me.

Tub

If you are still using a tub for showering/bathing, there are a couple of inexpensive ways to make it a bit safer. Place adhesive non-slip safety treads on the tub floor to provide extra grip for your feet. Add temporary grab bars to make entry and exit easier. There are several options available, including those that install temporarily by using advanced suction design. I used these successfully until we had our custom shower built. Lastly, make sure you have a non-slip bath mat to step onto.

Tub Modification

Recently, a member of our local support group shared their experience with a tub modification that we had never seen before (another reason to find and attend a local support group). The process is called a 'TubCut', turning an ordinary bathtub into a walk-in bathtub, without all the expense of a full tub conversion. This lower threshold, along with strategically placed grab bars, and perhaps a shower stool may be a good alternative solution for some folks. Here is a link describing the process

<https://www.youtube.com/watch?v=t72teDgFOEE>



Walk-in / Roll-in Shower

As early on as possible, start preparing for the day when you will need to roll in to your shower. This means not only getting away from a typical tub/shower design, but also avoiding a step into a shower. Find a reputable contractor who is willing and able to custom build a shower to meet your specific needs. I have found that shower with a regular shower head, a handheld sprayer, fold down seat, lateral drain and plenty of handrails works great for me.



Lateral drain example



Pump Soap

Bar soap is tough enough to hold onto when you have working hands/fingers. If you're tired of dropping the soap, switch to a liquid soap in a pump dispenser. I have found that most stores carry a large Dove soap pump that works great in the shower.

Tile Choices

While polished marble and porcelain are beautiful, they are also a major slipping hazard in the bathroom, especially for folks with stability issues. The most important tile choice is for the shower floor itself. I recommend a smaller tile with a honed finish. This gives you grip both from the texture of the tile, and from the grout lines between the smaller tiles. Small hexagon tiles are my recommendation in the shower itself. The tile you will be stepping out of the shower onto, with wet feet, is also very important. Assuming you will use a bath mat to step onto, the floor tile can be a bit larger, but avoid slippery tile to be safe.

Toilet Height

Even folks with healthy legs complain about squatting down to a standard height toilet. My first recommendation is to purchase a 'comfort height' toilet. That will get you 17 ½ inches of height. I found that this was better, but still difficult to squat down to and get up from with diminished leg strength. I found a 'Toiletvator' on Amazon.com that was very easy to install under the toilet and gained me an additional 3 ½ inches of height making bathroom time much more comfortable.



Electric Toothbrush

As your hand/arm strength diminishes, you may be tempted to invest in an electric toothbrush. Let me warn you, I tried this, and it was an epic fail! The one I bought was designed to run continually for two minutes, with your mouth closed. The second you open to spit, toothpaste and spit will splatter your vanity, your mirror, your shirt and anything else within a three-foot perimeter. This may work for others, but I had to share my experience.

Drying Assistance

While I have not tried this device, it was recommended to me by a fellow ALS patient via PatientsLikeMe, and it sounds interesting. The Tornado Body Dryer can be safely installed, by a licensed electrician, directly in your shower to dry you completely without the need for a towel. This can be very helpful for folks who have lost hand dexterity and/or arm strength. <http://www.tornadobodydryer.com/>



Urinals (sorry ladies, men have an advantage here)

Since I am in my wheelchair for 14+ hours each day, we needed to figure out a way for me to urinate without doing taxing transfers all day. We decided that the urinal would become our way to accomplish that. After some trial and error, we have found a good position with my power chair to allow me to relieve myself using the urinal. We have this memory setting saved on my chair so that my caregiver simply pushes one button to get me into position to do my business, and hits another button to return me to my home position. The one we use (pictured below) is described on Amazon.com as a 'female' urinal, but it is the sturdiest one that we have found.



When I go out, I always have a few disposable urinals with me, just in case the need arises. When the bathroom isn't accessible, or you simply can't wait, these come in very handy. They are compact, so they can be carried discreetly. The brand that I use is called Travel John, available on Amazon. They contain an absorbent material, which prohibits leaks.



Shower Chair

There are a wide variety of shower chairs available online or at your local home health store. I have read positive reviews for 'My Shower Buddy', which has several available models. My insurer, like most, would not cover the cost of the shower chair, so I elected to check with my local ALS Association chapter loan closet. They have lent me the chair pictured below. It took a few showers to get used to it, but we have now settled into a routine with the chair that has greatly reduced the stress of showering, both for my wife and myself.



Bidet

So if the electric toothbrush was my worst investment, the bidet was by far my best! Don't get me wrong, they aren't cheap, mine was \$650. Once you lose hand dexterity, it can be difficult to feel clean after a bowel movement. If you're like me and want to retain some level of dignity for as long as possible, you will be reluctant to ask for help with wiping. There are a wide variety of bidet attachments which fit on a standard or elongated toilet and simply replace the existing seat. Installation is quick and easy. I love my BioBidet 2000, and have never felt so clean and fresh.



When I am traveling, I purchase a less robust bidet attachment, which one of my travel companions installs for me in the hotel bathroom. For about \$40, it does the job for a few days. I have had good luck with the Luxe Bidet Neo 120 - Self Cleaning Nozzle - Fresh Water Non-Electric Mechanical Bidet Toilet Attachment, available on Amazon. Also, consider an over the counter stool softener to make evacuation more comfortable.

Chapter Seven –Assistive Technology

Thankfully, over the last decade there have been great strides made in technology that have been adapted for the needs of ALS patients to extend both workability and independence. No longer do PALS need to feel disconnected and isolated. Your local ALS Association Chapter should be able to demonstrate the available options and help you decide what best fits your individual needs. If you are still in the workforce when you are diagnosed, and wish to continue working, your employer has certain obligations under the Americans with Disabilities Act. They are required to make ‘reasonable’ accommodations to allow you to keep working. Therefore, they may be able to provide you with some of the Assistive Technology described below.

Voice Banking and Text to Speech Software

If you forget everything else you read in this book, at least remember this! The day you are diagnosed, if not before, begin voice banking. Recording your unique voice versus using the standard computer generated voices provided by text to speech applications allows you retain your individualism. Based on the software you choose, there are several recording options available. They range from simply recording common phrases to actually making a digital copy of your voice so that everything you type is ‘spoken’ in your own voice. Prices vary widely and certain software is not compatible cross-platform, i.e. Apple versus Microsoft or Android operating systems. So be sure to do your research before deciding what product best suits your needs. I suggest checking out Project Revoice. <http://projectrevoice.org/#pats-story>

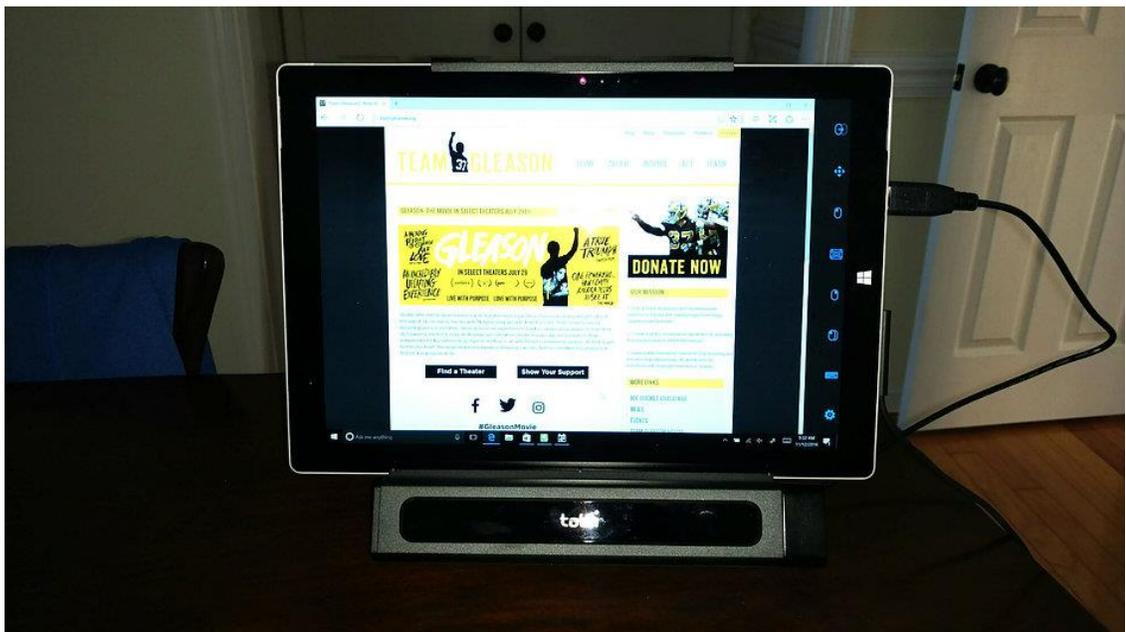
Boogie (pronounced boo-jee) Board

For those with speech issues, but who still have the ability to write, a boogie board is a good low-tech, affordable option for communicating. It allows you to write your thoughts on the board and showing it to the person you are communicating with.



Eye Gaze

I have written this entire guide on my Microsoft Surface Pro using PCEye Mini by Tobii Dynavox. This is just one of the commercially available eye tracking devices that lets users with limited hand dexterity access and control tablets or personal computers using eye movement. The use of this device allowed me to continue working for at least six months longer than I would have been able to without it. Personally, it's been a savior in retirement as well, allowing me to remain connected to the world around, without the use of my hands. It takes a bit of practice to get used to. I suggest getting it before you have to rely on it fully, in order to work with it and be comfortable by the time you truly need it. The addition of an external battery (MAXOAK 50000mAh 6 Port -5/12/20v- Portable Charger External Battery Power Bank for Laptop & Notebook) allows me to roam around all day without being tethered to the wall.



Environmental Controls

Using your tablet, or depending on the clarity of your voice, using Alexa, Google Assistant, or similar devices, you can control many electronic components within your household, including, but not limited to; HVAC, lighting, ceiling fans, blinds, locks, and doors. The options are only limited by your imagination and budget. Team Gleason has begun helping those in need by providing these devices at no cost to the patient or family. Depending on how much you are trying to automate will determine whether you simply need a tech savvy friend, a handyman, or a licensed electrician.

Keeping in Touch

Once my finger dexterity deteriorated to the point that using a smartphone for calls or texts, I was afraid that reaching out to people in real time would be difficult, if not impossible. Eye gaze technology allowed me to email, but folks are not always checking their email. That is when I started using Facebook Messenger as my primary means of communication. I can call, FaceTime, or message any of my family or friends, as long as they have a Facebook account. And the best part, it's free. The couple of friends that didn't use Facebook, were more than happy to create an account so that we could easily keep in touch.

Chapter Eight - Travel Tips

If you enjoyed traveling before you were diagnosed, don't let ALS make you a hermit. The number one piece of advice I have for you is to allow yourself more time. Everything you do with ALS requires more time and effort, travel is no different.

Call Ahead to Hotels to Confirm an Accessible Room

Of course you can request an accessible room when you make your reservation. Unfortunately, I have learned that this is not a guarantee that one will be available when you check-in. I would recommend you call just a few days before arrival and reiterate your need for an accessible room, explaining your condition if you are comfortable with that.

Ensure Airline Reservations Indicate Your Handicap Status

Unfortunately, there is no easy way to simply add your handicap status to your frequent flyer profile. Once you make your flight reservation, call the airline and ask them to add an indicator to your reservation. This will alert them of your special needs and keep you from being bumped off your flight in an oversold situation.

Allow Extra Time for TSA Screening

If you are wheelchair bound, this is even more important. Make sure to inform the TSA screener of any physical limitations, such as the inability to stand, raise your arms, etc. TSA will be accommodating, but the process will take extra time. Calling TSA in advance has produced mixed results, at best. Your message may or may not make it to the TSA screeners. I suggest not wasting your time calling. Just arrive a bit early.

Allow Ample Connection Time

When booking air travel, avoid any connections with less than an hour between flights. This is particularly important if you are wheelchair bound, as you will likely be the last to deplane.

Consider First-class Airfare

Assuming you are likely traveling less often, consider splurging for First-class seats. Not only will you travel more comfortably, but I have also found airline personnel to be much more accommodating when you hold a First-class ticket.

Scooter Rentals

If you don't yet have a scooter or power chair of your own, and you will be visiting a destination that may require a lot of walking, research in advance whether there are scooter rentals available. Destinations like Las Vegas, Orlando, Atlantic City and others all have multiple providers willing to deliver to your hotel at reasonable rates.

Consider Destinations Within Driving Distance

If and when air travel becomes too cumbersome, consider destinations that you can drive to. I have found that the main benefits, particularly after I was in a power chair, are having your own vehicle, and being in control of your own schedule. Living in Richmond, VA, we were spoiled to have close access to a great airport. Prior to my diagnosis, we flew nearly everywhere we visited. I would have never thought of driving to New York, it was simply 'too far to drive'. But, since we have our accessible van, we have visited Atlantic City, Philadelphia, Pittsburgh, and have visited New York three times. Don't worry about 'making good time', instead enjoy the journey. Also, don't try and do too much on any given day. Separate travel days from event days, to avoid wearing out your caregivers, and yourself.

Sporting Events

I have refused to let ALS to keep me from attending baseball games, so I have a lot of experience here. The most important piece of advice I can give you is to plan ahead, the earlier the better. Second, call and speak with someone in person to explain your needs so you get the best seats available. If possible, ask for seats close to a family restroom. Arrive early, because elevators are not always plentiful, or conveniently locate, and tend to get busy closer to game time. Lastly, I am not suggesting that you break any laws, but I am just sharing the fact that no one has ever questioned what was in my cup when I entered the stadium. ☺

Chapter Nine - Fundraising

If you are like me, you hate asking anyone for anything, let alone money. You are going to need to get over that. This disease is demanding and expensive. Even if you think you have spectacular insurance, deductibles, co-pays, non-covered services and many other unexpected costs will add up. As soon as you share your condition with Friends and Family, they are going to want to help. Assisting with fundraising gives them a way to do so.

Establish a Dedicated Account for Fundraising

You are going to want to be able to track all incoming and outgoing transactions independent of any other funds. Head down to your local bank and let them know what you are doing and why and let them decide what type of account is best for you, with the lowest fees. For me, I opened a dedicated savings account with no fees as long as I maintain a \$300 balance. I suggest you name the fund something very straight forward like 'John Doe ALS Fund', which will make check cashing much easier. Due to limitations in the 501(c)(3) IRS tax law, funds established for an individual or family cannot be granted 'Non-Profit' status. Therefore, any donations to the 'John Doe ALS Fund' are NOT a tax deductible expense per the IRS.

Set up a PayPal Account

The easier you make it for the people to donate, the more likely they will be to do so. It takes under ten minutes to set up a PayPal account, and link it to your dedicated fund raising account. The set up costs nothing, and there are no fees to send or receive funds.

Develop a Website

This might sound like a daunting task, but it's much easier than you would expect. There are plenty of websites that offer inexpensive, easy to use templates and will host your site for a nominal monthly fee. If you have digital photos available, can type and drag and drop, you can do it. If not, find a more tech-savvy friend to help. Having a place to tell your story, advertise upcoming events and keep everyone updated regarding your fight is critical to your fundraising success. I used wix.com to develop my site, but web.com, godaddy.com and many other sites are available to help you customize your website.

Settle on One Annual Main Event

Putting on a successful fundraising event takes time, patience and a lot of coordination. If you have folks willing to lead this effort, let them. I suggest you act more like a consultant and save some energy. Choose an event that is likely to interest your friends and others, and will be fun. Suggestions include; golf tournament, music festival, volleyball tournament, softball tournament, corn hole tournament, steak fry, or any other event you think will draw a large, fun crowd. The key to a successful fundraiser is gathering sponsors. Solicit local businesses that you have patronized, such as Restaurants, Bars, Dry Cleaners, Realtors, Financial Advisors, Employers, Dentists, Optometrists, or anyone you think would be willing to donate in exchange for recognition and signage at the event and on your website. To put things in perspective, my first annual golf tournament took a committee of five, six months to organize, but raised over \$17,000. The second and third annual events raised over \$20K each. Their dedication and attention to detail have made each event a tremendously fun time and everyone now looks forward to this annual event.

Support Your Local ALSA and MDA Chapters

Hopefully you will learn that your local chapters of the ALSA and MDA can offer you and your family great support. From support groups to loan closets and research grants, their help is immeasurable. Help them help you and others by supporting their fundraising events. You don't need to make large donations to help. Simply organizing a team of your friends and family for their annual walks will add up and help immensely.

Chapter Ten - General

In addition to the physical tips and tricks I have included here, there are several general pieces of advice that I think can lead to a better quality of life for you and your caregiver.

Keep a Positive Attitude

I know this can be difficult at times, but try not to focus on things outside of your control. Be thankful for what you do have, especially for the loved ones around you. Try to keep your sense of humor and don't be afraid to make fun of yourself. Being angry and bitter about your plight will only result in people withdrawing and making things worse. If you stay positive, you will find that others around you will be more comfortable and willing to help. I like to say "Attitude is Everything!"

Patience is a Virtue

Everything takes more time now. Showering, shaving, dressing, eating, leaving the house, etc., will all take more time than they used to. Be patient, adjust your schedule accordingly to avoid unnecessary frustration. Most importantly, be patient with your caregiver. They are trying their best. Don't take out your frustration with the disease on your loved ones.

Be Your Own Advocate

Your Doctor and their staff may be great, but remember that they have dozens of other patients, and likely other diseases to monitor. They can't be expected to monitor daily ALS developments. You will need to keep up with developments yourself and bring them to your doctor's attention if you feel you may benefit from a new treatment. For example, I read that doctors who were prescribing Nuedexta for pseudobulbar affect were seeing improved speech and swallowing in their ALS patients, I immediately sent the article to my doctor and had it prescribed, with positive results.

Accept Help from Others

Losing your independence can be difficult. But, you will need to learn to choose your battles. Maybe you can struggle to get dressed all by yourself. But it's probably smarter to accept help and conserve that energy for socializing with your friends and family. Similarly, keep in mind how much your primary caregiver does every day, so when others are around, ask them for help instead.

Spend Money Wisely

ALS is an expensive disease, there are no two ways about it. You will be faced with constant financial decisions. Make sure to consider the long-term, particularly with large expenditures. For example; while I was still driving, turning the ignition key with my right hand became difficult. We considered having a push-button start installed. The cost was nearly \$1,000. Instead, I dealt with the inconvenience of snaking my left hand through the steering wheel to start the car. Six months later, I stopped driving because my arm strength diminished too much to feel safe. Had we spent the money on the short-term solution, that's a \$1,000 less I would have had for the accessible van that we ultimately needed.

Managing Setbacks

Setbacks are going to happen; they are simply part of the disease. But, don't let small setbacks become large steps backward. For example, if you normally feed yourself, but you come down with a cold that zaps your energy and you need help eating that is fine, but don't let that become the new 'normal'. As soon you regain your strength, get back to feeding yourself as long as you are able to.

Stay Connected to Friends and Family

As your disease progresses, your natural instinct will be to withdraw and limit your comfort zone. Fight that instinct for your own good, and for the mental health of your caregiver. The more friends and family that are around and you can get comfortable accepting help from, the less likely you are to burn out your primary caregiver.

Monitor and Manage Your Energy Output

Make sure to plan your days' schedule so that you have energy for the things you want to do. For example, if you are planning on socializing with friends in the evening, conserve your energy during the day, perhaps even get a nap in. Much like the Mountaineers climbing Mount Everest are careful not to expend all their energy on the summit, reserving energy for a safe descent, be sure not to over extend yourself in whatever you do. Make sure to reserve enough energy to safely make it home and into bed.

Find and Attend Local ALS Support Groups

Only others with ALS understand what you are going through. Take advantage of support groups to meet others and learn from them. Sharing your experiences is beneficial for everyone. I was skeptical at first, attend a few sessions and decide for yourself.

Pamper Yourself

If you used to get manicures and/or pedicures, but have stopped because of travel difficulties, talk to your fellow PALS to see if they know someone that will come to your home. The same holds true if you miss going to the salon, see if there is someone who will come to you. If you are able to continue with these niceties, it will help you feel better about yourself and keep a positive attitude.

Faith

Regardless of your religious upbringing, I feel it's important to have faith in your beliefs. Personally, I had wandered away from my faith when I entered adulthood, but I am thankful that ALS has helped me regain my faith. I have no doubt that this has allowed me to be at peace with my condition and whatever my future holds.

Clinic Visits

If you are lucky enough to have access to a multi-disciplinary clinic, regularly scheduled visits can be very valuable. But, they can also be very exhausting. Here are a few tips to ensure that you are getting the most out of your visit;

- Schedule your appointment early in the day, if possible.
- Ask if you can meet with the Respiratory Therapist to measure your FVC first, before you are tired from meeting with all the other disciplines.
- In the weeks leading up to your visit, make notes of what topics that you would like to discuss. If possible, share them with the clinic team in advance.
- My particular clinic is at a teaching hospital. While I don't mind the students observing my visit, I have asked that their participation be limited to observation only. Previously, I was getting more tired from answering questions from both my doctor and the students.
- Don't be afraid to make a suggestion about changes that could be made to make your visit work better for you. Personally, I have requested that we have only one discipline in the room with me at a time. I found it overwhelming to converse with multiple people simultaneously.

Physical / Occupational Therapy

Physical and Occupational Therapy can be very beneficial, if you get the right therapist. If you are doing therapy and feeling like it's a waste of time, don't be afraid to change vendors. Remember, you are paying these folks, so make sure you are satisfied. Share your experience with your Clinic team and ask them and/or fellow PALS for recommendations. My first experience with occupational therapy completely turned me off. It took me over a year to give another therapist a try. Now I am very glad that I did, because I am feeling the benefits every day.

Try to Group Your Requests

This advice comes directly from my wife, my primary caregiver. For instance, instead of asking for water and fifteen minutes later, asking for assistance with the bathroom, try and plan ahead and ask for assistance just once and knock off as many needs as possible. I have tried to adopt a philosophy of limiting singular requests as much as possible. At least in my house, this has reduced the number of sighs and eye rolls.

Tax Preparation Tips

To ensure that you take full advantage of the tax credits that you are entitled to, I offer you two important pieces of advice. First, create a file, either on your computer, or an old school paper file folder. Every time you pay for anything related to your illnesses, such as; medical supplies, copayments, home modifications, accessible vehicles, etc., file away the receipt. If you are not sure if the expense qualifies, file it regardless. Make sure that you also keep copies of other tax related documents together, like charitable donations, personal property tax records, etc. This will keep you from scrambling around come tax time. Secondly, enlist a qualified tax preparer to file your return. While you may have prepared your own tax returns in the past, I assure you that it is worth the few hundred dollars to ensure that you are taking full advantage of the tax credits that you are entitled to, based on the current tax law, which changes yearly.

Keep Your Mind Active

It's easy to fall into the trap of simply watching TV or browsing social media. While that is fine from time to time, don't get sucked into this all day, it doesn't keep your mind active enough. Thanks to advances in technology, there are many options available to you. If you enjoy reading, but can no longer hold a traditional book, explore the world of audio books. I carve out a couple of hours each afternoon to listen to an audio book and give my eyes a rest from my eye gaze device. The most common audio book application is Audible, which is fine, but costs can add up over

time. I prefer an application called Overdrive, which is free and allows you to borrow titles from your local library system. All you need is a library card. The application is very easy to use, and lets you search by whatever genre may interest you. If you enjoy history, Bill O'Reilly has some great audio books that he has written and also narrates. I definitely recommend listening to Killing Lincoln, about the last few days of the Civil War and the subsequent assassination of Abraham Lincoln.

Another great option is listening to podcasts. Most are free and readily available through iTunes, Stitcher, or many other services. Podcasts are available on any conceivable subject from sports, comedy, politics, history, religion, celebrity news and my personal favorite, true crime. I personally love True Crime Garage and The Frozen Truth podcasts. Happy listening!

Rings

Keep an eye on your any rings that you may wear, particularly if you wear a wedding band. As the disease progresses, and we become more sedentary, we tend to have more swelling in our extremities. I have heard of many pALS having to have wedding bands cut off. Thankfully, we caught mine just in the nick of time. With some ice, soap, and a lot of my wife's strength, we were able to get mine off in one piece. I have replaced it with an inexpensive silicone band, available on Amazon.com. Some pALS opt to wear their wedding band on a necklace, which is another safe option.

Hiring Caregivers (For Example, Certified Nursing Assistants)

Most insurance carriers will cover a limited number of "skilled" nursing visits each year. But, before you progress to the point of needing a nurse, unless you specifically have Long-term Care (LTC) insurance, most insurers will not cover the cost of "personal care", leaving you on your own to find assistance with daily activities. Having someone to assist and lessen the extraordinary burden on your primary caregiver is vital to maintaining a healthy and happy home life.

You might expect that it would be easy to find someone to help for 10-20 hours each week. I assure you that finding someone affordable, reliable, and that you are comfortable with, can be a difficult task. Because I have a supportive family and a great network of friends, I was looking for someone for 2-3 days each week to assist me with using the bathroom and feeding me lunch. I went through three caregivers very quickly before finding a caregiver who has been great. From talking with my fellow PALS, I am told that I am very lucky to have found a reliable resource this

quickly. I don't write this to sound negative, but to set reasonable expectations for you. Unfortunately, after over a year of a great relationship with my primary caregiver, he informed us that he was relocating. Below are recommendations that my wife wrote up based on our experience finding a replacement for him. Good luck!

Below are recommendations I would start with before calling an agency:

1. Make a schedule of the PALs daily or weekly routine. It doesn't have to list everything, but it helps give the agency and caregiver an idea what to expect. For example, Jason laid out his tentative schedule for each day for the caregiver:

Monday
8:00 Transfer Jason to wheelchair
Dress him for the day
Wash eyes and brush teeth
Wash face and hands
Turn on TV to channel to 574, volume 13
Give Jason a cup of ice water
Prepare and feed him oatmeal
- include morning tablets in oatmeal
Give him one eye drop in each eye
9:00 Change TV channel to 590, volume 10
Set up Microsoft tablet
10:00 Give Jason ice coffee and riluzole pill
~11:30 Help Jason urinate
12:30 Heat up lunch and feed him & Gatorade
3:00 Give Jason afternoon pills in applesauce
3:45 Help Jason urinate
Give Jason a cup of ice water
4:00 Turn off TV

2. How many days a week are you looking for? How many hours in a day?

3. Can friends or relatives help? I setup a Google calendar and shared it with my friends/family. They picked what days they could help me out and what task and I filled in the rest. If you have a good network, I would start with this. It will save you money. We did this for about 6 months before we went with an agency

4. Is the PALs more comfortable with a male or female caregiver? This is important to know. Jason only wanted a male. Male caregivers are very hard to come by and typically want more money. We started with male and when our caregiver left, we went through a string of females.

5. Talk with your PALs on their comfort level of having a stranger see them naked. People have reservations and is typically the main reason why people delay getting help. Most caregivers have worked in a facility of some type, so they have seen it all.

Once you decide to go with an agency, here are a list of questions we learned to ask along the way:

1. How much do they charge per hour?
2. Can they administer pills or just give reminders?
3. Does the agency have a minimum shift requirement? If so, how many hours is it? Most places are minimum 4 hours. Pick a work schedule that fits your needs. Don't let them bully you into paying for more hours than you really need.
4. Once you determine a schedule that fits your needs, ask if they have people that are available for those shift hours. I say this because we wanted to fill 28 hr. a week – 4 days at 7 hrs. per day and hired an agency. After 2 months of no shows, caregivers being late, etc. we were told that people like 12 hr. shift or 48 hr. work week. I couldn't accommodate those hours, so it was hard for the agency to fill our hours.
5. If you are like me and still work during the day, you need to establish with the agency and caregiver a “ground zero” leave time. If you need to leave the house by “x” time, communicate that to them so if the person is running late or not coming you need to know by “x” time.
6. Depending on your PALs care, be sure to ask the agency about specific care needed. Different agencies will allow their CNAs to do different things:
 - a. Wound care or feeding tube care/bandage
 - b. Shaving
 - c. Trimming nails
 - d. Run errands
 - e. Administering of Medicine
 - f. Valid licenses for transporting to appointments
 - g. Bathing, dressing, etc.
 - h. Laundry
 - i. Breathing machines, cough assist machines, suction machines
 - j. Light house cleaning
7. I put light housing cleaning in because it is good to know what they will and won't do. In the beginning, I didn't want them to do anything. After several rounds of all different types of caregivers, I now address it up front. You need to be up front with your expectation and what is not acceptable. For example, not leaving a mess for you to clean up, (this is huge, as I went through 2 caregivers where I was cleaning up more after them than I was Jason); having them wash bed sheets or towels; making the bed; taking out the trash; washing all dishes used for the day, all these little things add up to you doing less when you get home.

8. If you are using a lot of electronics, vet the agency and caregiver stating you need someone that can quickly pick up how to use these devices. If you hear them say “oh that is fancy” RED FLAGS, RED FLAGS.
9. Depending on what stage the PALs is at, will determine care needs. I have found a lot of agencies don’t deal with ALS patients, so you need to educate them on the do’s and don’ts. For example, excessive talking can be draining; ask yes or no questions not “do you want this or that?”; educate them on what makes the ALS patient tired; don’t ask questions or try to conversate when feeding; if food needs to be cut up into small pieces, tell them; etc.
10. Lastly, the agency/caregiver work for you! If they are not a good fit, fire them or ask for another caregiver. Don’t accept or settle for poor or unacceptable treatment. It will only add more stress to the situation.

Additional things to think about:

I have a list on my fridge that lists Jason’s medicine, Date of Birth, height, weight and our address. This way if 911 is called, the caregivers can give the list to the paramedics. I also keep a copy of Jason’s DNR on the fridge as well. We have been told that EMS workers are trained to look on the fridge for these documents.

Chapter Eleven - Tips for Caregivers

First and foremost, THANK YOU for everything you do! We could never fully express how grateful we are for everything you do for us! You are the rock that we lean on for support every day and for that we are eternally grateful. This is intended to give you some insight into our daily struggles and our thought processes. I also suggest caregivers read the Epilogue written by my wife.

Patience, Particularly in the Morning

Having patience with us is very important, but it's never more important than first thing in the morning. Mornings are particularly tough to for us. When we wake up, our muscles lag behind. Please be patient with us as we warm up like an old car engine. And, likely any medication that we have taken the night before, such as muscle relaxants or pain medication, has worn off, leaving us stiff.

Daily Struggles

On average, each day is tougher than the previous day. Yes, we have good days and bad, but nearly every day we are a bit weaker than the last. If we drop something, make a mess, or fall down, please don't get angry, we already feel bad enough. We are trying to retain what little independence we have left, and that may change every day.

Your Mood is Contagious

Your attitude is contagious. If you are frustrated, we are frustrated. If you are happy, we are happy. Sometimes keeping a positive attitude can be very difficult for us, please look for those down periods and offer positive encouragement.

Requests

Please understand that if we ask for something, we have already pondered whether there is any way we can get it ourselves, or if we really need it. Know that there are many times throughout the day we would like to have something, but we forego asking because we don't want to bother you.

Ideas

If you think you have an idea of a way to do something that may be easier for us or conserve some energy, please share. This is a learning curve for us too. We are a team and we will get through this together, learning as we go.

ALS Is Exhausting

Please understand that our bodies never relax. Even if we seemingly haven't done much, we will be tired at the end of the day. That is not a good time for meaningful discussion.

Accept Help from Others

We understand how difficult this is on you. Don't be afraid to accept help from others. Surely folks have said "let me know if you need anything", take them up on it. Maybe it's making some food, running to the store, taking us to an appointment or something else. Friends want to help, let them. For example, we have friends come over twice a week to feed me dinner so that my wife can go to the gym.

Maintain Your Own Identity

It's important that you retain your identity. Make sure to carve out some time for yourself every week. While you are a caregiver, don't let that define who you are. Remember, it makes us happy to see you happy.

Find and Attend Local Caregiver Support Groups

Only other ALS caregivers understand what you are going through. Take advantage of support groups to meet others and learn from them. Sharing your experiences is beneficial for everyone. My wife and I were skeptical at first, attend a few sessions and decide for yourself.

Phrase Questions Wisely

When communication becomes a challenge, you can make it easier by phrasing your questions so they seek only a 'Yes' or 'No' response. For example, instead of asking "Is your food too cold, or is it OK?", simply ask "Is the temperature OK?" Yes, or No responses take a lot less energy.

Suggested Reading

A terrific article written by fellow ALS Warrior Rick Jobus. A must read for all ALS Caregivers <https://alsnewstoday.com/2018/09/12/als-manners-etiquette/>

Chapter Twelve – Navigating Insurance and Social Security

I worked in the Medical Insurance field for my entire adult life. That doesn't change the fact that I have no patience for the seemingly endless hoops that every insurance company makes us jump through. My best advice is to begin all processes earlier than you think you need to, and try to have more patience than I do! (that bar is set pretty low)

Medical Insurance

As soon as you are diagnosed, assuming you are still working, begin researching your employer's health benefit options so that you are prepared for the next open enrollment opportunity. I suggest a plan with the lowest deductible and out of pocket maximum. While the premiums are a bit higher up front, it will save you in the long run. I also suggest that you consider putting money into your Health Savings Account (HSA) or Flexible Spending Account (FSA) to cover the full amount of your deductible.

Short / Long-Term Disability

Another item to start researching as soon as you are diagnosed, assuming you are still working, is your employer's short and long-term disability benefits. It's essential for future planning to know exactly what you can expect both from a financial standpoint and from a lead time requirement. Make sure to keep your boss in the loop about your condition, and hopefully you will be able to work together on the timing of your short then long-term disability filing. Most employers will allow you to start the filing process about thirty days before your scheduled last day. This is important so that you can get all your paperwork completed and approved to avoid missing paychecks as you transition from active pay to disability pay.

Social Security Disability Insurance (SSDI)

If you have worked in the United States and paid into the Social Security system, your ALS diagnosis qualifies you for Social Security Disability benefits, regardless of your age. It's important to know that you will not qualify as long as you are still actively working. Once you cease working, even if you are collecting short or long-term disability benefits from your employer, you may begin the application process. The application can be completed online, but allow 3-4 hours. A few days after completing the online application, I suggest a follow up call to your local Social Security office to ensure they are aware of your diagnosis so that they can fast-track your application. SSA has an expedited procedure for processing terminal illness cases to ensure that a favorable decision can be made expeditiously. The code word for this type of case is "TERI" case. Please note, even after approval, there is a five month waiting period before any benefits are paid out, please plan accordingly. For more information, click on the link provided in the Resources section of this guide.

Medicare

If you are not already age (65) qualified, you will be eligible for Medicare benefits once you have qualified for Social Security Disability Insurance. Congress passed legislation in July, 2001 benefiting the ALS Community. The usual 24-month waiting period for Medicare was eliminated for SSDI recipients disabled by ALS. Medicare entitlement now begins the first month the recipient receives cash benefits (approximately 5 months after an individual is deemed disabled.) For more information, click on the link provided in the Resources section of this guide.

Chapter Thirteen - Resources

No one has paid anything to be promoted here. I am simply including resources that I have found helpful through my experience.

ALS Association

Obviously based on name recognition, they are the most widely known ALS related charitable organization. Not only do they raise a ton of money for ALS research, the local chapters also provide great patient and caregiver support. They operate loan closets, support groups, and provide other ancillary services to help patients and their families. www.alsa.org

Muscular Dystrophy Association

The MDA is probably best known for the Jerry Lewis Telethon each Labor Day weekend. What folks don't know is that the MDA is the single largest source of funding for ALS. Since their inception, they have awarded more than \$344 Million in ALS research grants alone. The local MDA chapters also provide various support services for ALS patients and their families. www.mda.org

Team Gleason

Founded by former NFL player Steve Gleason, Team Gleason helps provide technology assistance to ALS patients in need. In fact, they provided the Microsoft Surface Pro and Tobii eye gaze device that allowed me to share this information with you. www.teamgleason.org

Northeast ALS Consortium (NEALS)

The name is a bit misleading. Initially founded as a collaboration of scientists from the northeastern U. S. working on ALS research, the consortium now has participation worldwide. They regularly host free webinars presented by ALS experts that I find very beneficial, and educational. www.alscosortium.org

ALS News Today

I check this site daily to keep up to date on the latest developments in ALS research. Almost nothing slips past their attention, so it's worth a daily look.

www.alsnewstoday.com

Patients Like Me

This is a great place for patients to connect with others to share and learn from each other. Considering a new treatment? Review the outcomes of others who've tried it. Struggling with a symptom? Check with others for advice to address it. You can share as much or as little as you wish, anonymously or not. www.patientslikeme.com

ALS Untangled

Founded by Dr. Richard Bedlack of Duke University, ALSUntangled helps patients with ALS to review alternative and off-label treatments. www.alsuntangled.com

Social Security Disability Insurance and Medicare Benefits Overview

The ALS Association has published some very helpful information about both SSDI and Medicare, with additional links.

<http://www.alsa.org/als-care/resources/publications-videos/factsheets/professionals-guide-govt-benefits.html>

Department of Veterans Affairs (VA)

If you are active or separated military, first and foremost, THANK YOU for your service. If you are a veteran with ALS, you are rated at 100% disabled and there are major benefits from the VA. Contact the VA IMMEDIATELY! The Paralyzed Veterans of America (PVA) will help you get all the forms submitted and push them through. The ALS Association has also published some very helpful information about Veterans benefits related to ALS, with additional links

<http://www.alsa.org/als-care/veterans/service-connected-benefits.html>

Performance Health (formerly Patterson Medical)

If you are struggling to find a unique item, or you aren't sure exactly what you are looking for, check out Performance Health. They have a tremendous inventory of helpful items. www.performancehealth.com

Bed Bath & Beyond

If you like shopping in person versus online, so you can look and feel for yourself, this is a good place to look for utensils, cups, plates, shower stuff, etc. Don't forget your coupons. www.bedbathandbeyond.com

Amazon.com

If you are not already an Amazon Prime member, go ahead and sign up now. Amazon sells a ton of aids that will help you out, usually at a more affordable price than your local pharmacy or home health store. www.amazon.com

Funding Sources

If you are in need of funding assistance to help with items not covered by your insurance, there are several organizations that may be of assistance. Keep in mind, these are fairly small organizations. Their ability to assist with grant money will be determined by their available funds, and the volume of requests at any given time.

ALS Ride 4 Life <https://alsrideforlife.org/>

Hark ALS <https://www.hark-als.org/>

ALS Guardian Angels <http://www.alsguardianangels.com>

Project Main Street <http://projectmainst.org/>

ALS Foundation for Life <https://alsfoundation.org>

Epilogue – By Deborah Clement, Jason’s Wife and Caregiver

From a Caregiver’s perspective – When that special day comes and you are standing in front of your significant other saying your vows and you both repeat “for richer or poorer and in sickness and health”, did you ever believe you would be tested? I know I never did. Yeah sure, maybe 20 or 30 years down the road when we were in our golden years but not in our 30’s and 40’s.....

Jason and I met playing volleyball. We were both very active in sports and socializing with friends and family. When the day came for us to be married, I knew I would spend the rest of my life with this man. When it came to kids, neither one of us wanted to be tied down. You could say we were selfish or we just loved being independent. The motherly instinct was not something I had either. The combo of the two allow Jason and I to travel and experience new things.

The day Jason was diagnosed with ALS was the day my world came crashing down. My whole way of life has/is changing daily. Those motherly instincts I didn’t have, started creeping up from the depths with a lot of cobwebs on them. Let’s just say dusting those off has been a challenge. I feel bad that I’m not more maternal as I bet it could have saved us some fights.

In regard to Jason’s tips for Caregivers, I would agree with them wholeheartedly. But there is something else to consider that he didn’t mention. There is no way to prepare for this! No matter how many books you read or internet searches you do, each person is different. There is a learning curve for both the caregiver and the patient. The tips sound simple, be patient, be positive, ask for help, accept people’s help, maintain your own identity, etc. but it is a lot harder than you think. Your coping mechanisms are tested to the fullest. Mine is laughter or making a joke. It is hard to be patient, positive and in my case, make a joke when you are tired, pissed off from work, exhausted, and you just want to come home and do nothing. You can’t. You have to suck it up, put on a brave face and be there for that person. Because no matter how crappy of a day you had, theirs was worse! This can be hard for people. This is still hard for me today. I do things I don’t want to do every day because I love him. And I know deep down, if the roles were reversed, he would do the same thing for me. He would probably do a better job than me, sadly. My advice for an ALS caregiver is, it sucks! You see the person you love at their lowest, and when you think it can’t get any worse, it does. The whole process is trial and error. Talk to each other

and don't try to guess what the other person wants or needs. I can't believe after all these years Jason still can't read my mind. And most importantly, embrace and cherish the good days and try to make as many of those days as possible.