

Almost from the moment we first learned of my diagnosis, my wife and I realized that we would have to reinvent our lives. But in those first, early weeks, we had no idea what that really meant; we had no idea to what extent everything would have to be reinvented.

My ALS was caught fairly early. I was 49 at the time I was diagnosed, in 2006. My symptoms were limited to some twitching and muscle weakness in my upper arms/shoulders. I was still doing everything in my life as usual. I was working full-time, traveling for work, still driving, still doing household projects, etc. I have been living now with ALS for almost 20 years. Over that time my body has undergone a number of changes, and each time something changes our family has had to adapt. In the paragraphs below, I outline some of the challenges and adaptations that have helped me to live with ALS - to live as full and complete a life as possible.

But let me say here at the outset, I am keenly aware of three great advantages that I have had in confronting my ALS. It is entirely possible that since Lou Gehrig, I am the luckiest man to ever get ALS. Here is how I can say that;

First, the progression of my ALS has been unusually slow. This has given me time to figure out and plan for my needs. I have not been overwhelmed by losing function faster than I could adapt.

Second, I was an engineering manager throughout much of my career. As such I was well compensated and I am in a position to be able to afford much of what I need. Not only that, my employer was one of the last of the large, traditional old school corporations. Employees were provided with robust health insurance, short and long-term disability insurance, long-term care insurance, life insurance and a traditional pension plan. All of these have provided me with significant economic benefit. I truly represent the tail end of the "good old days" for this kind of corporate employment.

Third, my formal training and career were all in science/engineering. Much of my career was spent finding the right technical solution for problems. I was always somewhat inventive (during my work years I authored 13 patents). So much of what I have been doing has come fairly naturally to me - that is, figuring out and finding the best devices that could help me compensate for my loss of function.

These advantages that I have enjoyed definitely do not extend to most of my fellow travelers with ALS. I constantly wonder how people, especially those without the time and money that I have enjoyed, can manage to maintain a decent quality of life. Their struggles are heartbreaking.

Part One - Early Adaptations

At the time of my diagnosis, or shortly thereafter, my first thought was to keep working as long as possible, primarily to buy time while we figured out our financial situation. We had two kids, a freshman and senior in high **school**. Getting them through college and launched in life was our top priority. I endeavored to keep my diagnosis secret from my employer, out of concern that if they knew, I might become a target for

layoff (my employer at the time was going through some major restructuring/downsizing). It worked. I was able to continue working for three more years before retiring on disability.

While I continued working I had to incorporate several adaptations to compensate for my weak arms and weakening hands. As I recall, I think the first challenge was starting my car. I could get the key in the ignition, but had a hard time turning it. This problem had a simple solution - an enlarged key fob. I found this device on a website for people with arthritis. With this, I only needed to push or pull the blue handle in order to turn the key.



Photo 1; my key fob

The next workplace challenge for me was using a computer mouse. Because a mouse is manipulated off to the side, my weakened shoulders made this difficult. After first trying a trackball, the best solution I found was something called a roller mouse. This permitted all mouse activity to be accomplished with small movements of my fingertips, right in front of me. I used one of these for years both in the office and in my home.



Photo 2; working at my computer in my home office (with my roller mouse)

At about the same time I started to have trouble gripping a zipper, making it difficult to go to the bathroom when I was at work. I solved this by wearing suspenders and putting a large ring on my zipper. I found some 1 inch diameter metal rings on Amazon. I placed one of these on all of my pants through the small opening at the tip of the zipper. I was able to place one finger through the ring and pull my zipper up or down. Suspenders held my pants up while I was doing this. This plus the switch to boxers enabled me to go to the bathroom on my own when needed. No one ever noticed these things, or if they did, they were at least to polite to ask me about them.



Photo 3; my zipper pull, seen on a Christmas trip to Barcelona with my wife and son (photo taken by our daughter)

I retired on disability three years after my diagnosis. During my last few months of work I had finally lost the ability to type. I compensated for this through the use of a microphone and dictation software. I have continued to use these adaptations to this day. Some of my colleagues at work had clearly noticed some issues, and when I started using a microphone at the office I'm sure they were suspicious. But again, no one really said anything.

Part two - Retirement

My wife continued working for 10 years after I retired. During that time I kept busy with three big projects. First, realizing that my travel days were limited, shortly after my diagnosis my wife and I decided to take as many family trips as possible. Because our kids were in college and high school and always had summer jobs, and my wife was a schoolteacher, it turned out that the only time everyone's vacation aligned was Christmas. So we started planning and taking big Christmas trips. We were able to pull off six of these trips, from 2007 to 2012.

I was still working when we took our first two Christmas trips. We went to Puerto Rico (at the recommendation of a colleague). We rented a small cottage on the edge of a shallow inlet protected by a large rock formation. It made an ideal place for me to enjoy the water. But one day while my wife and daughter were walking up the beach, I spotted a sandbar projecting out into the large bay next to our protected inlet. I started walking out on this sandbar so I could enjoy the warm water and watch the sea life on the floor. I was in about chest deep water, looking down at the bottom when I was unexpectedly lifted up by a larger wave and deposited about 10 feet from the sandbar. I suddenly found myself in much deeper water. Not anticipating any problem, I started to swim back toward the sandbar. To my utter surprise it seems that because of my weak arms and shoulders, I was no longer able to swim! After a brief moment of panic, I rolled over onto my back and tried to kick my way back toward the sandbar. But the incoming waves kept pushing me away from the sandbar, so I turned around and started kicking toward the beach, a couple of hundred feet away. It took me a while, but I eventually made it to the beach, thoroughly exhausted. During that long swim it definitely occurred to me that I might drown.

Did that frightening experience stop any further thought of beach vacations? No! After that experience we went back to the same spot in Puerto Rico the following year, and for the next half-dozen years continued going to Sanibel/Captiva for spring break to visit my father. But from that time on whenever I went near the water I was always with either my daughter or son (both were on the swimming team in high school and both were lifeguards). I also purchased a cheap paddleboard on each trip which I would keep tethered to my wrist whenever I was in the water. That worked for me like a flotation device and at the end of our vacation I had the enjoyment of finding some young kid at the beach to whom I could give this away (we didn't want to have to lug it back on the airplane).



Photo 4; wading in the protected inlet with my wife and son (and paddleboard)

After I retired, our Christmas trips became more adventurous. We started traveling to Europe. I spent significant time in the fall planning these trips.

As we were tourists, these trips generally involved a lot of walking. The last couple of years when I was still walking, I started having problems with my head hanging down as my neck got weaker. At the Northwestern Medical ALS clinic, I was prescribed a neck brace which propped up my head. This made it much easier for me to walk.



Photo 5; wearing my neck support on a Christmas trip to Rome with my wife and son (photo taken by our daughter)

This extended my ability to walk for a year or two. But eventually I had my first fall. I tripped on a cobblestone street in Venice. As I wasn't able to use my arms to break my fall, I landed headfirst and was knocked out. I was taken to the local hospital in a Venice ambulance, which turns out to be a boat. I spent a night there and another day or two recovering at our hotel. We continued on our trip, but alas this ended our family Christmas trips overseas.

After retiring, besides travel, another of my projects was a fun one. Some of my former colleagues pulled me into a volunteer project to try and improve attendance in struggling Chicago public high schools. I worked for a year and ½ at Orr high school on the west side of Chicago. My contribution to the project was getting accurate data for the team. For the first year I was able to travel every day to the school, but for the last six months of the project I was losing the ability to drive on the freeway and so worked from home.

Somewhere around 2011 I finally had to give up driving. I would still go out frequently with my wife on the weekends. After my second fall/hospitalization (again I tripped and landed headfirst) I began wearing a bike helmet and started using a portable wheelchair whenever we were out of the house.

At this time I was also going through changes in how I would eat. For a couple of years after I retired I could still use traditional utensils. As I got weaker I found that I could hold a fork with both hands and prop my elbows on the table. To spear a bite, I would just rock my forearms toward the plate, stab what I wanted, and then rock my forearms back until I was holding the bite up to my face. This worked for about a year or so, and then I changed to “bobbing” for food. I would keep my hands in my lap and just bend over at the waist to grab a bite of food right off the plate with my mouth. I ate this way for a couple of years, both at home and in restaurants! I did draw a lot of attention in restaurants, especially from children. It was not uncommon for me to look up after grabbing a bite of food and see a young child pointing at me and whispering to their mother, until the mother, with a horrified look on her face, saw me and pushed the child’s hand down while saying a stern word or two to the child. When this happened, I tried to make eye contact with the child so I could smile and wink to let them know that we were both in on the joke.

Eventually my abdominal muscles got weaker and this stopped working. Since then someone has had to feed me.

The only main adaptation I incorporated into our house at this time was to replace all of our doorknobs with lever handles. I did not need to grasp these to open the doors. I could just drop my hand behind them, press down and pull the door open with my arm.

Since I was now using a desktop microphone and voice recognition full-time to manage my computer, I built myself (well actually, my daughter built for me) a new PC with components selected for being very quiet. I had to replace that machine some years ago, but again sourced and built a computer to be essentially silent

Another significant set of adaptations during this time involved daily care; toileting, shaving, teeth brushing and getting dressed. For dressing, I started wearing only pullover shirts and sweaters. I would grip the hem of the shirt in the back with my mouth, bend over and drop my arms through the shirt into the sleeves. Then I would stand up, throwing my arms up as high as I could, before letting them fall to my sides as they pulled the shirt down over my head. As there were always suspenders on my pants, I could drop my hands down inside the hanging suspender, hook my thumb inside the suspender, and then propping my elbow on the counter lift the suspender up onto my shoulder. I used a button hook to fasten my pants, and my trusty zipper pull to pull up the zipper.

As for going to the bathroom by myself, the main challenge was that I could not grip toilet paper. I purchased a cheap waterproof stool at Bed Bath & Beyond. I would sit on the toilet right before taking a shower. Rather than using toilet paper, I would just put a bar of soap on the stool, sit down over the soap and slide back and forth to wash myself. This approach allowed me to go to the bathroom, take a shower and get dressed by myself for several years.

Shaving and brushing my teeth were actually not very challenging. I had used a rotary toothbrush for some time, so this continued to work well. As for shaving, I did have to switch to an electric razor. I could grab that with both hands, prop my elbows on the counter and manage to move my face back and forth across the razor getting a reasonably good shave. I must admit however, that I always did (and still do to this day) miss shaving with shaving cream and a razor!

I even managed to continue clipping my nails, with the use of the nail clipper sold for people with arthritis.



Photo 6; nail clipper sold for people with arthritis

I could even clip my toenails with this device, by putting it on the floor and stepping on the handle with one foot, while I clipped the nails on my other foot.

There was one adaptation I looked into and seriously considered, but ultimately did not adopt. In looking back, I'm glad I did not. This was an adaptation I considered to extend my ability to drive. I ***hated*** giving up driving. I gave it up because I could no longer grip the steering wheel. My feet/legs still worked perfectly on the pedals. During my last year on the road when I got in the car, I would just throw my hands up to the

top of the steering wheel and curl my fingers around to grip it as best I could. The steering wheel held up my hands. I drove quite conservatively, but knew in my heart that I was a hazard on the road. As I was facing the end of my driving days I found a company that could retrofit a car to be steered via a joystick in the driver's lap. My wife and I took a two hour trip to this company's location so that I could be evaluated for their technology. It cost about \$10,000 to adapt a car for this. I seriously considered it, but ultimately decided not to go forward. I'm very glad about that. I think it would have only bought me another six months of driving at best, so the expense would have definitely not been worth it. Of course this realization only works in hindsight. At the time, I have often found it very difficult to gauge the value of different adaptations, as I usually have no idea how long they will work for me.

Part three - Life in a Wheelchair

The really big "retirement" project we undertook was to figure out what we were going to do when I would have to start using a wheelchair full-time. Because we liked our existing house/location, and had done a lot of work over the years to improve it to our liking, our first thought was to see if we could make it into a "wheelchair house". The bedrooms and bathrooms were all upstairs, but still we forged ahead thinking we might convert our sunken living room into a master bedroom/bath. After some months talking with several home improvement contractors/designers we finally concluded that the narrow hallways, small doors and elevation above grade really made our house economically impractical for wheelchair conversion.

We then started looking for a house that could be more readily modified for a wheelchair. We were primarily focused on homes in our area, as my wife planned to teach for another 10 years or so. We thought a ranch home would be best. However we found that most of the ranch homes in our area were all built in the late 60s/early 70s and had the same problems as our existing house (narrow hallways/doors, small bathrooms and sunken living rooms). We next looked briefly at some existing new construction two-story homes to see if they would be amenable to adding an elevator. We also struck out with this approach.

We finally decided to bite the bullet, buy some property, find an architect and build a suitable "wheelchair" home.

We wanted property close to my wife's school (so she would not have to commute too far), walking distance to a train station, and fairly flat. We figured that we would have to get property wide enough to accommodate a first-floor bedroom, or plan on having an elevator. We thought proximity to a train station would be advantageous as we anticipated that at some point I would need caregivers, and we thought they were likely to come from the city. This turned out to be wrong. All my caregivers have been local, and have had their own cars. But proximity to a train station turned out to be a wonderful thing as our kids ultimately wound up living in the city and this made it much easier for them to visit us.

In 2012 we found and purchased a lot in the same town where my wife taught school. We had started working with a local architect, a husband/wife team. We liked their taste and sensibility very much, but ultimately lacked confidence in their understanding of what would make a house good for someone in a wheelchair. The second architect we found, and with whom we completed a design, had a designer on staff who was wheelchair-bound. He definitely understood what we would need, and that helped a lot.

We finished our plans by the end of 2012 and began construction in late spring of 2013. The house was finished in March 2014 and we moved in right away.



Photo 7; touring the construction site

The house was designed with a long straight hallway leading from the front door to the back. This allows me to move through the house with the minimum number of turns.



Photo 8; the main hallway as seen from the front door

There are three main rooms that I use, all on the first floor. They are all in a row off the main hall; my study (first door on the right), my bedroom/bathroom (halfway down the hall on the right) and the family room/kitchen (at the end of the hall). The doorways leading into my study, bedroom and bathroom are all 4 feet wide (double doors, each 2 feet wide).



Photo 9; 4 foot doorway leading to my study (two sliding doors, each 2 feet wide)

All the flooring is flush between rooms, and the entry doors have low rise thresholds. This enables easy wheelchair movement throughout the first floor.



Photo 10; flush threshold looking out through the front door

One adaptation of which I am particularly proud is that we were able to build the house essentially at ground level. The lot we purchased is fairly flat, with a gradual 18 inch drop in elevation from the back to the front. The challenge in building a house at ground level in our climate, especially with low rise thresholds on the doors, is how to manage snowmelt in the spring. I worked with a civil engineer who designed a flush drainage system in front of the back doors which captures any water as the snow melts, and diverts it through underground piping to the front of the house which is about a foot lower in elevation. For the 11 years we have lived here this system has worked perfectly.



Photo 11; flush drainage system just outside the back door

The other advantage of having a gently sloped lot, is that we were able to make the front walk double as a wheelchair ramp. From the street it is not obvious that this house is wheelchair accessible.



Photo 12; front walk leading up to the front door which doubles as a wheelchair ramp

Because we were building the master bedroom/bathroom, we were able to make the bathroom especially suitable for wheelchair use. I did as much research as possible into what I would likely need. Much of the online research suggested that bathtubs were more important than showers. That turned out to be wrong for me. I do have a deep bathtub, which I have never used. However I planned for a large roll-in shower, and that I use every day.



Photo 13; my shower chair in the roll-in shower

One adaptation which has proven quite useful happened quite by accident. One of the “tips” I read about was that large closets are very useful for storing a Hoyer lift. I contacted the local Hoyer lift supplier to find out how big I should make the closet. They put me in touch with their on-staff designer/architect. When I posed my question to him, he immediately told me that if we were building a bedroom/bathroom from scratch, a ceiling mounted lift would be a much better solution. He explained that the most significant cost of such a lift for an existing home was tearing out the ceiling to put in the required reinforcement needed to take the load. But as our ceiling wasn’t yet built, adding the necessary structure would be very low cost. He worked with our architect to get what was needed incorporated into the plans. For the first year we lived in the new house I was still walking (at least indoors). And for the first year I used a wheelchair in the house I could still walk a few steps and make manual transfers. But when I finally needed a lift for transfers, putting in the ceiling mounted lift was quite easy.

The track for the lift covers a space next to my bed/over my bed for transfers. It then continues on into the bathroom and over the toilet.



Photo 14; the ceiling lift track going from my bedroom into the bathroom/over the toilet

Part four - Living in the wheelchair house

We moved into the new house in the spring of 2014. I was still walking and could still climb stairs. The first few months in the new house I was able to visit the upstairs a couple of times and the basement once. But I soon lost the ability to climb stairs, and since that time have stayed on the main floor.

In the spring of 2014 and the following school year, I was home alone while my wife was at work. I had lost the ability to make myself lunch. In our old house Meals on Wheels only served the elderly, and not the disabled, so for the last year we lived there I hired a local woman to come in and make me lunch. Though our new house is only a couple of miles away, in this neighborhood Meals on Wheels serves the disabled as well, so I signed up for their lunch service.

I spent my days at home, mostly in my study at my computer. Because I had no use of my hands/arms, I installed devices throughout our home that could be voice activated (when I say that "I installed", that really means one of my two children installed, as they are my primary IT help);

- Amazon Echo devices in every room on the main floor. I use these to listen to music and podcasts, and as an intercom between rooms.
- An Amazon Echo Connect on the telephone. This allowed me to answer and place phone calls through any of my Echo devices. (In 2024 this device was discontinued. I have yet to find a really good solution for placing/answering phone calls, but to at least enable me to make 911 calls I have signed up for Alexa Emergency Service).
- A smart switch to enable me to turn my computer monitor on/off.
- Phillips Hue light bulbs in my study so that I can control the lighting.
- A Fire Cube on the TV. This enables me to turn on the TV, find a show, change the volume, fast-forward etc.
- A Ring doorbell and an August door lock. These allow me to see who is at the door if the doorbell rings, talk with them, and then unlock the door to let them in if needed.
- Nest thermostat. This allows me to control the temperature/humidity in the home from my computer.

On weekends I frequently went out with my wife while she was running errands, wearing my bike helmet and using a portable wheelchair. I was still able to walk into the garage and with some help get into the car.

In the fall of 2014 as the school year was starting, I realized that even when I was just walking around the house I was starting to get a bit unsteady on my feet. So I started wearing a fob around my neck. It had an accelerometer, so if I fell it could place an emergency call for me without having to push any buttons (it was made by Phillips).

In the fall of 2015 I was getting to the point where I didn't even trust myself walking around the house, so I finally started using a power wheelchair full-time. I could control my wheelchair via a joystick mounted on the right foot plate. I could lift my right foot and set my heel on top of the joystick. I was able to use this joystick for the first four years that I was in my wheelchair. With the joystick I could go as fast as I wanted, and it was relatively easy to track in a straight line. With the joystick I would often drive to the library in the summer (it's only a few blocks away), and even went a few times into the town center for a morning coffee/doughnut. But eventually I lost the ability to lift my leg up. Too bad. That joystick worked really well!

Because I could still move my neck, I switched to using a headrest to control the wheelchair (the headrest can be seen in photo 15). There are proximity sensors in the headrest. When I press my head back, to the left or right it powers the chair forward, or executes turns. This works well enough around the house. But it is not so effective outdoors. It's too difficult to track straight, and I generally go much slower. So outdoors someone has to drive me using controls on the back.

Being in a wheelchair meant that I needed an aide to come in during the day while my wife was at school. For this I used the long-term care insurance from my employer. Shortly thereafter we purchased a wheelchair van so that I could still get out and about.

Once I had a caregiver, I decided to start "practicing" with my BiPAP machine. I was prescribed this a year or two earlier, but never really used it much. I knew that I would someday need to use one (to compensate for my weakening diaphragm). So to get used to it, every afternoon I started watching a movie with my caregiver, wearing my BiPAP machine. Within a year or two I started wearing it at night. I now use it every day starting after dinner. Some days, when I'm feeling short of breath I wear it in the afternoon. I even have a portable version that can clip to the back of my wheelchair so I always have it with me when I am out of the house. My BiPAP machine can be seen on its stand in photo 9, next to my desk.

Another change that occurred once I got into a wheelchair full-time, was that my ankles almost immediately swelled up. I started wearing compression socks, and switched from a conventional bed to a hospital bed. The hospital bed allows me to elevate my head and feet at night, which is both more comfortable for me and helps manage the swelling in my feet and ankles.

Part Five - How I Live Today.

Now my days are quite routine. Sticking to a routine makes things both easier for me and my caregivers. A caregiver arrives every morning at 8:30 PM. She transfers me to my wheelchair. I drive out to the kitchen for a glass of water, a cup of coffee and sometimes if I am hungry a muffin or a piece of toast. I use a conventional glass and straw for my water (someone has to hold that up for me while I drink). For my coffee I have an insulated cup with a long flexible straw so that I can drink it on my own, at my own leisurely pace.



Photo 15; enjoying my morning coffee at the kitchen table.

I have my morning coffee at the kitchen table in the winter. But as the weather warms up I have my coffee most mornings on the back porch. The double doors to the porch are visible just off to the right in photo 15. In the summer, on good days I will even go outside to the back patio for my morning coffee - after the patio table/umbrella are set up of course. Because the house is at ground level in the back, and the threshold in the door from the back porch to the patio is flush, it is very easy to drive my wheelchair onto the patio.

At about 9:15 AM or 9:30 AM I drive back to my bedroom and drive directly into my bathroom. I raise my wheelchair up about 18 inches and recline back. My caregiver then shaves me with an electric razor and brushes my teeth with an electric toothbrush. I have a cup and straw to get water after brushing my teeth, and an old measuring cup with a handle which I use so I can spit. I then drive back into the bedroom and park my wheelchair next to my bed. I transfer to my bed where I get undressed. For the first six years in this house I would then transfer using my ceiling lift from my bed into the bathroom and onto the toilet. After toileting I would then transfer to my shower wheelchair and be rolled into the shower to take my morning shower. I now skip the toilet (as my abdomen has continued to get weaker it has gotten too difficult for me to transfer onto the toilet and remain seated there). Instead I now go straight to my shower chair and do my toileting in the shower with a bucket placed under my shower chair.

After my shower I transfer to my bed, where I get dressed and do my range of motion exercises. I return to my chair, do my cough assist and some days, if needed, I have a little vacuum device to clean out my nose and sinuses. I then drive my wheelchair to the study (I can be seen in my study, at my computer, in photo 8). My caregiver cleans up the bathroom. This is my routine every single morning, and we are generally done by 11 AM or so.

At this point my caregiver leaves , unless we are going out. Rarely in the winter, but in good weather, I try to get out once a week or so. I have my wheelchair van, and I can generally maneuver my wheelchair down the front walk, up the ramp into the wheelchair van. I park next to the driver and there are straps which hold my wheelchair in place. Outings might be to Costco or Home Depot, to visit friends or go to the doctor. Generally when we go out I try to pick up some lunch on our way back. On days when I'm at my computer all morning, at noon I drive back to the kitchen for lunch.

After lunch I return to my computer where I generally spend my afternoons. I read several newspapers/newsmagazines, correspond with friends via email, work on the occasional project (like this one), pay the bills, do the grocery shopping etc. Occasionally I like to rock back and listen to a podcast. But whatever I'm doing, at around 5 PM I head back to the kitchen for dinner. After dinner I take my pills. Then my wife and I usually watch the news, jeopardy, and either a movie, documentary or sports event until about 9 PM or 10 PM. I then drive to my bedroom and my wife transfers me to my bed. I usually watch another movie and get to sleep by about midnight.

Part Six: Conclusion

These years with ALS have required one constant adaptation after another. I have come to realize over this time that my battle with ALS is fought on three fronts; agency, dignity and hope. Being able to adapt my environment so that I can do as much as possible for myself is my fight for agency. Dignity for me long ago stopped being about physical dignity. I now think of it as mental dignity. Finding adaptations that work is something like solving a puzzle. This activity is one of the projects that provide me with a sense of dignity. As does working on projects like this one. And finally having the right adaptations provides me with hope. Hope to me does not mean that tomorrow needs to be a better day. It only means that tomorrow should be a good day. And for the way I live, almost every day is a good day.

I enjoy my life. I look forward to getting up every morning. I have plenty to do and almost never get bored or depressed. It has taken a lot of devices and adaptations so that I can feel this way. I realize how lucky I have been that I've been able to make the kinds of accommodations that enable me to continue having a good life. I want everyone who suffers from ALS to be able to have a similar outcome. That unfortunately is not the reality for many of my compatriots. There are some wonderful organizations helping people cope with ALS, such as Les Turner and Team Gleason, to name a few. I wish more resources were available for all of the organizations like these, serving the ALS community as they help everyone try to maintain their best possible lives.