

ADAPTIVE EQUIPMENT I HAVE USED¹

by Warren Peascoe

My legs were paralyzed when I was four and a half. To walk, I have used braces (KFAO's) and crutches for over 65 years. With my braces off, I am able to crawl a short distance such as from the bed to the bathroom. I hope that some of my experiences and ways of coping may help others.

Knowing that I would always need durable medical equipment influenced my career choices. I realized early that I would need to be a "knowledge worker". I also decided that I would have to work for major corporations so that I could get group medical insurance. Beyond braces every couple of years, I didn't know what I would need or when I would need it. I have always been very frugal with expenses to maintain adequate savings.

I have used several creative types of adaptive equipment. As a child my grandfather made a platform out of four 2x4's with four castors on the bottom. He drilled four holes on top so that a chair could sit securely on the platform. I could either "scooch" the chair by shifting my weight or use my crutches as pushers and propel myself backward. I used this platform around the house as I grew up. In college, I got a wooden chair from the college that would fit on the platform. I used it to go from my room, pushed by crutches, to the shower room at the end of the hall, and then sat on the chair while I showered.

In grad school, there was a valve in my research lab that was too high for me to reach. I used wheeled platform stairs with hand rails

on the sides and a platform on top. I could get up about two steps and kneel on the next step which put me high enough to easily reach the valve.

At work, I once was given a desk chair on rollers. It rolled too easily on the concrete floor for my liking. I asked for, and was given, a rubber backed throw rug which slowed the chair just enough. Fortunately when I started using a scooter, a co-worker, who had already used a scooter for a few years, had fought and solved most of the accessibility problems. Together we got access to most parts of the plant.

BRACE HISTORY

I don't remember my first braces. When the family moved from California to New Jersey, Connecticut, Hawaii, and then back to San Pedro, various brace shops were used. I think some were military or VA and some were private and paid by the March of Dimes. When we were back in San Pedro, the March of Dimes moved me to a brace shop about an hour away because the local shop was just too expensive. This shop had a "master brace maker" and he made new braces for me even through graduate school. He lived half way between home and the shop. Whenever I broke a brace, Mom would drop off the brace at his house early in the morning and pick it up in the evening when it was repaired. I scheduled new braces for my visits home from graduate school in Illinois. It wasn't until I started working in New Jersey and then

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Connecticut that I had to locate a brace shop on my own and use my company medical to pay for braces. The first couple of new braces went through with no trouble.



*President Roosevelt's Braces from 1930's.
Compare to Warren's Braces 80 years later.*

When I checked about getting new braces the second time in Connecticut, I found that the company insurance policy did not cover durable medical equipment. The policy was re-negotiated every two years and durable medical equipment was excluded in that contract. The local brace man explained the cost of braces; if I paid for braces myself, it would cost about 10% of my annual salary; if my insurance paid for the braces, the cost would be about 8% of my salary and I would only pay 20% of that; if the state paid for the braces, it would cost about 5% of my salary. The cost depended on the negotiating power of the payer. At his suggestion, I arranged for the state to pay for my braces and I repaid the

state. To get the state to pay, I had to have my first social worker as an adult. She described helping a fellow get an artificial arm. Her secretary was in a state of panic, when he called and left a message. "I am coming to the office after lunch and I am coming armed!"



Warren's Braces with Plastic Thigh Support

BRACE DETAILS

I've been fortunate that long leg braces (KFAOs) work for me. Typically I put the braces on first thing in the morning and take them off last thing at night, just like with my glasses. With the braces on, I used to be able

to swing through for long distances using crutches, walk around the house without crutches, and stand for several hours to work in the lab. Now even with crutches, walking a few feet on a flat non-slip surface is very slow and difficult. It activates the carpal tunnel pain in my wrist. I use the wheelchair all the time.

Until I started using a scooter, I was quite hard on the braces and my general rule was to replace them every two years. This insured that I had a useable backup pair, when my current braces broke. Now my braces last several years since I use a power wheel chair.

I saw a display at Warm Springs of Franklin Roosevelt's braces made in the 1930's and I was surprised that they were essentially the same as my current braces. Both had metal rods, with a hinge at the knee, attached to a shoe, a locking mechanism to keep the rods straight, kneepads to keep the leg from bending, and a cuff to hold the thigh and support the body weight.

Over the 65 years that I used braces, I have seen some changes, but these have been almost totally in the materials of construction. My early braces were steel. Then aluminum was tried, but it fractured so double thick aluminum was used. Although aluminum is lighter than steel, the thicker aluminum actually weighed more than the steel. Now a high grade surgical steel is used and it rarely fractures. Where it has fractured, I have it reinforced when new braces are made.

The locking mechanism has improved. Initially sliders wrapped around the joint and had to be individually lifted to allow the leg to bend. Some of Roosevelt's braces had this locking mechanism. Now there is a "bail" that

goes in back of the knee and into the locking mechanism on both sides. When the bail is lifted, both knee joints unlock at the same time. This is much more convenient for sitting and both locks can be opened with one hand. Some of Roosevelt's braces and some modern braces have a release lever on the side to unlock the brace so the leg can bend.

Until the mid-1990s, my braces were made with a metal band that went around the thigh. The band was riveted to the top of the rods and covered with leather. This provided a fairly comfortable support for most of my weight when I was standing. The brace men suggested that I try plastic, but I resisted for several years. I've heard it said that old polios are the most difficult to introduce to new types of braces, I believe it to be true. Finally I switched from leather to plastic for the thigh support. This did reduce the overall weight of the braces. Whenever I am evaluated for new braces, the conclusion is that my current type will be the best for me.

Making new braces is a major undertaking and requires several visits to the brace shop. First a paper tracing is made of each leg and it is annotated with careful measurements. Then when the braces are partially finished, there is a rough fitting to make sure no mistakes were made. This is to check that the hinges are indeed at the knee and that the length and shape of the metal rods does fit my legs. When the braces are finished, adjustments are often required to allow me to stand comfortably.

Working with many brace makers, I have also developed some minor modifications from the standard brace to improve the function and comfort. These are describe below and shown in the pictures of my braces.

A. PLASTIC THIGH SUPPORT

To make the plastic thigh support, a plaster cast is made of my thigh. This is removed and used to make a plaster mold of my leg. A sheet of plastic is then vacuum formed around the mold of my thigh. The plastic surface has a texture from the mold that was used to vent and form the plastic. This texture causes me to get rashes on my legs. I have found that sanding the plastic smooth with the finest sand paper available greatly reduces the rash. I have talked with other people about plastic and they have suggested using a cloth lining (nylon stockings or other material). However if the cloth folds during use, I find that it leads to pressure sores on my legs. Screws that attach the plastic to the braces, need to be carefully sanded flush so that there are no sharp edges.



Locking Mechanism with Tygon Sleeve



*Locking Bail with Protective Leather Sleeve
in Position When Brace is Locked*

B. LOCKING BAIL AND PROTECTIVE SLEEVE

When the locking bail is lifted up, it unlocks both sides of the brace at once. This is probably the greatest improvement I have seen in functionality of the braces. The bail rubs against my pants when I sit down and tends to wear the pants. I have a piece of plastic (Tygon) tubing slid over the bail before it is mounted on the brace. This saves my pants when I sit down on a hard seat, and it is slippery so that my pants don't hang up on the brace.

I also put a leather sleeve over the knee joint. It is simply a piece of leather that wraps around the lock and is riveted closed on the

top so that it is free floating on the brace. This keeps my pants from becoming caught in the locking mechanism and make my pants last a lot longer.

C. KNEEPADS



Kneepads with Extension

My knees bow in and press against the inside metal of my brace. I have the kneepad extended on one side (the inside to make it asymmetric). The extension goes between the brace and my knee and provides some padding to protect the skin. If there is a bump in the leather or a knot in the thread, I will pound it down with a hammer or even file off the bump.

D. CALF SUPPORT

Since I am knock kneed, the calf support leather is riveted on the outside and in the back (outside of center) and there is no rivet on the inside. This allows me to use a very

slight tension to pull my leg to the outside of the brace.



Calf Support

E. REINFORCED ANKLE STIRRUP

Several times I broke the stirrup that attaches my shoe to the brace right at the bend. Before the braces are made, I have a second layer of metal welded to the stirrup to make it twice as



Reinforced Stirrup and Double Sole on Shoe

thick. I have not been able to break the reinforced stirrup.

F. EXTRA SOLE ON MY SHOES

Before the shoe is used for a new brace, I have a second sole put on the shoe from toe to heel. I then have a half-sole or new heels added when the shoe starts to wear out. Typically I can wear the same pair of shoes for the life of the braces.

G. SANDING LOCKING MECHANISM AND SHOE EYELETS

The edge of locking mechanism is very sharp when it comes from the factory. This can cut through the kneepad straps and/or cut through the knees of my pants. Using very fine sand paper, I lightly sand the edges to dull the sharp edges.

I also role a small cylinder of sand paper (sand on the outside) and pass it lightly through each eyelet on the shoe. This removes any burrs on the inside of the eyelet and keeps the shoe lace from breaking.

CRUTCHES

My first crutches were the wooden under the arm type. I can remember the therapist teaching me to use a “four point” gait (left crutch, right foot, right crutch, left foot) and then the “two point” gait (left crutch and right foot move together, then right crutch and left foot). I tried “Kenny sticks” but the cloth around my lower arm did not give me the stability I needed. When fore-arm crutches

became available, I found that they worked very well. I used them with the cuff on the inside to give me more arm stability.

After the Korean War, I got a pair of heavy duty fore-arm crutches used for rehabilitation of veterans. These used thicker tubing and had really monstrous handles. This type of crutch went out of production until the Viet Nam War when they were again manufactured. The basic crutch was just about indestructible. I did break the cuffs and got pretty good at taking out broken screws and replacing them. Finally I drilled holes completely through the metal block to which the cuffs were mounted and put a nut on the end of the screw that stuck out. Much easier than removing a screw without a head. Modern crutches come with this modification.

When the crutch tips wore out, I discovered that there was a metal disc embedded in the rubber to prevent the crutch from punching through the tip. The heavy duty crutches were bigger than this disc. I would put a washer that was the same diameter as the tubing in the bottom of the crutch tip. If I didn't have the right size washer, a quarter worked in an emergency.

I believe that the huge handles delayed the onset of carpal tunnel syndrome. When I developed PPS, I began using civilian fore-arm crutches which were noticeably lighter. These have very thin handles. As suggested in Leff's² book I put a piece of foam pipe insulation over the crutch handles. This spreads the load on my wrists. Whenever I see a person using crutches, I tell them of this suggestion. Now with carpal tunnel, my

² Wenzel A Leff, MD *Traveling Without a Spare—A Survivor's Guide to Navigating the Post-Polio Journey* 2011 WAL Publishing LLC p.147

wrists start to hurt after only a few steps, even with the foam insulation.



Crutches Left - Heavy-Duty Korean-War Era Crutch with Large Handle. Right - Current Crutch with Smaller Handle.. Center - Current Crutch with Pipe Insulation Added with Duct Tape to Enlarge Handle. Note that the Cuffs are Used so that They are Open Away from the Body.

It didn't take me long to discover that swinging through was faster and a lot more fun than a "two" or "four point" gait. I also found that it took less energy to swing through. Doctors told me not to swing

through because it would ruin my shoulders when I got older. They were right as I now have arthritis, bone spurs, and tendonitis. Even though my range of motion is now severely limited in my "good" arm, I would still choose to swing through. Keeping up with friends and being able to do more things was just too important. Swinging through was also a neat way to cross a flooded street gutter without getting my feet wet. I would put the crutches in the middle of the puddle and then swing across. The trick was to really keep my feet high.

Using crutches forced me to be very aware of the floor; always look for anything that might be slippery. Any clump of dog hair, fuzz, or particles on the floor could lead to a fall if I put a crutch on it. Worms that crawl on the sidewalk after a rain are a special hazard. If I see any change in the reflection from the floor, I always use my crutch as a probe to see if it is wet and slippery. If the floor had any hint of being slippery, I tried to wedge my crutch tip next to the wall so at least one crutch can not slide. While I was walking the halls at work, I claimed I was the floor inspector.

I developed one trick with my crutches. If a piece of paper fell on to the floor, I would put both crutch tips on the paper. Then twist the crutches to make the paper bulge up and bring the tips together. Using the crutches as long chop sticks, I could pick up the paper and drop it on a higher surface that I could reach.

AUTOMOBILE

To get my drivers license as a teen ager, my parents put hand controls on the family station wagon. We lived in Los Angeles so there was a local dealer and it was no

problem. I have successfully used “right angle” hand controls (push down vertically for gas and push forward for brake) for all my cars.

My son had one incident when he was first learning to drive. He pushed the accelerator much harder than I or my wife did, and the slip-rod mechanism slipped out and jammed the accelerator all the way down. (The slip-rod mechanism allows a normal driver to push the accelerator and not have the hand controls move.) Luckily he had the good sense to simply turn off the key and coast to a stop. We all learned to be careful using the window crank to open the window at toll booths, or else we would hit the hand controls and cause the auto to accelerate.



Hand Controls for Car. Note Rotated Seat-Back. This Allows Warren to Transfer from His Wheelchair to the Driver's Seat.

My first experience in 1970 renting a hand controlled car was a disaster. The car was not there and my wife had an adventure driving in multilane traffic for the first time. Other rentals have gone smoothly and the cars were always there. Rental cars used “push-pull” hand controls (push forward for brake and

pull towards you for gas). If the controls were not adjusted exactly right, the auto could accelerate when the brakes were applied. The manager of a local rental agency once tried to drive the vehicle I was to rent. Instead of stopping, the auto accelerated and shot out into the street and around a corner. The hand controls pushed the accelerator when he stepped on the brake! When he got back, with an ashy complexion, he would not rent me the auto.

When I bought a new Omni after the gas crisis, I could not find a way to mount the hand controls. Normally the controls clamp to the steering column; the Omni was one of the first cars with such a complicated steering column that a clamp could not be used. I phoned all the hand control dealers I knew, but none had solved the problem. As a last chance, I called the state VA hospital and they were able to direct me to a manufacturer who solved the problem.

Every time I changed cars, I had to find a new place to put my crutches. With a bench seat, I put them on the floor behind my feet. Then bucket seats came into fashion, and I could put them between the door and the seat. Then that space became too small and the best I could come up with was to put them on the back seat. This required getting out of the car from the driver seat, closing that door, opening the back door, and reaching the crutches from the back seat.

When I first moved to Connecticut in the early 70's, I turned in my out of state license and was given a license which would be renewed in my birthday month. When the forms, that I was assured would be mailed to me, didn't show up, I went to the local DMV to renew my license. After standing in lines

for two hours, I came to the final window and wrote a check for my new license. The lady took my check and asked for my old license. She took one look at my license and exclaimed, “You didn’t tell us your license was pink. We don’t do pink licenses here. You have to go to the state capitol!” In retrospect I can think of lots of things I might have said quite loudly! I took a day off from work and drove to the state capitol and demonstrated to a very pleasant inspector that I could drive with hand controls. He explained that pink drivers licenses were for people who use hand controls and CERTAIN OTHER FELONS! This was changed a few years later.

SCOOTER, WHEELCHAIR AND MINIVAN

Years later when PPS began acting up, I knew that I would need to use a scooter. I visited suppliers over 100 mi away to decide what I needed. I also looked at vehicles that could carry a scooter. The best option was a converted minivan with a side ramp. Both of the front seats turn so that I can transfer to either position. The conversion just about doubles the cost of the minivan. It then took me about two years to acknowledge that I was finally ready for the scooter. Since I was still working, the company medical plan paid for 80% of the cost of the scooter. The van and its conversion were my responsibility.

My wife called several dealers that handled side-ramp mini-vans and found one that had just gotten a two year old trade-in with only 12,000 miles. We made the 100 mile trip the next day to purchase it. This first minivan was a VMI conversion with the ramp which slid under the floor. With the ramp under the floor of the van, my wife could easily enter the rear of the van and the passenger seat could

recline. The passenger seat still had to be forward and erect to allow scooter access.



Warren on Driver’s Seat in the Van. The Seat is Rotated and Moved Back so that He Can Transfer to His Wheelchair. The Seat Will Be Moved Forward and Warren Will Exit on the Ramp on the Side of the Minivan. Note the Far Forward Position of the Passenger Seat. With Wheelchair and Minivan, Warren Has Independent Mobility.

When we needed to replace this vehicle, we were advised to get a Braun Conversion which has a fold-up ramp. The deeper sides of the Braun ramp make it more difficult for a power chair to drive off the side and the ramp can hold more weight than the VMI conversion. The ramp must be folded into the van before the passenger seat can be put in a

reasonably comfortable position. My wife has to wait until I have transferred into the driver's seat and folded the ramp before she can get into the car. The wait can be damp and cold. The folded ramp also blocks access through the back door.

Some people drive from a wheelchair, but this doesn't look promising for me. Safety regulations regarding airbags, prevent shifting a single seat between the driver's and the passenger's position. This means that I would have to always be the driver or the passenger. I couldn't switch with someone else if I were tired or I would have to depend on someone else to drive me.

When it came time to replace the scooter, I decided a power wheelchair would give me more mobility in the house. I would also need tilt and recline features to control edema as well as the elevator feature to adjust the height of the seat. I was now on Medicare and worked with a local vendor to get approval from Medicare. I had to apply three times (each separated by six months) before Medicare approved the wheelchair with the tilt and recline features. Elevators still are not covered. I need this function to be able to stand with my braces from the wheelchair, so I paid for it myself. Medicare and my supplement insurance paid for most of the rest. The wheel chair costs about as much as a new car.

After about a year, my vendor had a fire and went out of business. When my chair broke, I spent hours finding a repair shop that would accept Medicare payment and was certified by the manufacturer. Normally the selling vendor is responsible for the repair, however since mine was out of business, no-one wanted my business. I finally found a repair

shop about 120 mile away that was in the same durable equipment region. I drive over there to get the chair diagnosed and then again after they received the parts for the repair. It can take two weeks to a month to get a repair completed! Oh yes, I had to send my old records from my doctor and from Medicare to establish that Medicare had paid for the chair and also the medical necessity of the chair! Medicare keeps requiring more and more documentation to approve repairs and I wonder if I will be allowed to get a replacement chair. My recommendation is to purchase all durable medical equipment through a large clinic or hospital rather than directly from a vendor. The hope is that the clinic will be large enough to make sure repairs are available.

Just like location, location, and location are the three most important things in real estate, the three most important things to me are independence, independence, and **independence!** The power wheelchair and the minivan give me the independence that I crave. I can still go anywhere by myself.

BI-PAP

I developed sleep-apnea a few years ago. I found that I could not tolerate the standard CPAP, it was just too hard to exhale. The CPAP delivers air at a constant over pressure to the patient during the entire breathing cycle to keep the bronchial tubes open. An alternative is a BIPAP which delivers air at a higher over pressure for the inhalation and a reduced over pressure for the exhalation. This reduces the work the diaphragm must do to exhale. The doctor prescribed a BIPAP for me and I use it regularly every night. Some mornings I wake up and am amazed how easy it is to breath! This has improved my

nighttime rest and daytime alertness. A recent article from PHI³ indicates that BIPAP might not be optimal for people with weakened diaphragm muscles.

NUSTEP AND EXERCISE



Warren Exercising with the NuStep. His Feet Are Strapped to the Pedals. The Handles Are Hard-Coupled to the Pedals so that Warren's Legs Are Moved as His Arms Move.

My ability to exercise, especially aerobic exercise, is very limited. I used to swim, but now it is too difficult to travel and change. During rehabilitation after a heart attack, I used a NUSTEP exercise machine. It is a sit-down elliptical machine with interlocked foot pedals and hand-levers. I use the hand levers for almost all the power and my feet go along for the ride. This worked so well that I

purchased one for myself and use it three to five times a week for aerobic exercise. I target six five-minute exercise sets with one minute rest between sets. This is followed by a five minute cool down.

I do a series of floor exercises prescribed by a physical therapist for my shoulder and back on mornings I am not going out. I also do some shoulder exercises with two pound weights.

MEDICAL TREATMENTS

I depend on my arms, especially my right arm, for all my mobility and independence. I must use my arms even to sit up on a bed and for all transfers. I am reluctant to undergo any medical procedure that will, even temporarily, reduce my ability to use my arms. After I had a pace-maker implanted, I was not supposed to use my arms for two weeks. I had to go to a rehabilitation hospital for recovery. I once talked with a thoracic surgeon. When I asked about rehabilitation after a possible chest operation, he wasn't aware of any place that could handle me. As a result my heart condition is now treated with poly-pharmacy. When my wrist or shoulder flare up, I use anti-inflammatories, pain relievers, and ice. I try to use the minimum dose of all drugs and avoid, as much as possible, those drugs for which a polio history is a counter indicator.

³ http://www.ventusers.org/edu/valnews/val_27-3jun13p3-5.pdf