

DEALING WITH THE PHYSICAL DECLINE FROM FSH MUSCULAR DYSTROPHY

SOME OBSERVATIONS AND INSIGHTS

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CONTENTS

PREFACE

- I. BACKGROUND AND PURPOSE
- II. GENERAL OBSERVATIONS AND SUGGESTIONS
- III. NEW CONSTRUCTION AND MAJOR RENOVATION
ISSUES AND IDEAS
- IV. HOME FURNISHINGS
- V. SUPPORTIVE EQUIPMENT AND HEALTH MONITORING DEVICES
- VI. MOBILITY EQUIPMENT AND SUPPORT
- VII. TRAVELING

PREFACE

Those of us with Muscular Dystrophy are very fortunate to be facing our challenges now rather than in the past. In just the last several years, there have been significant scientific breakthroughs regarding the sub-cell structures that cause some forms of M.D. These discoveries provide hope for many of us that potential cures are likely to be appearing on the horizon in the not too distant future. In addition, the accelerating pace of technological innovation helps us to live more independent and self-sufficient lives.

Muscular Dystrophy has been a major factor in my life for many years and I have had the opportunity to experiment with many aspects of trying to maintain or maximize the quality of life within the context of a constantly deteriorating physical condition. For me, trying to deal with the challenges involved can be divided into four interlocking principles.

- 1) MAXIMIZE SAFETY: This is the most important. It means always conducting activities in the least risky manner possible. This includes the use of special equipment, modifications to living environment, adjusting physical movements and procedures and not pushing beyond the body's capabilities.
- 2) ACHIEVE THE GREATEST FUNCTIONALITY POSSIBLE: This means always trying to find solutions to physical shortcomings that will achieve the best possible result with reasonable effort expended and at acceptable costs.
- 3) MAINTAIN INDEPENDENCE: This helps both physically and psychologically. Pushing for physical independence helps provide the mental toughness to aggressively pursue principles 1 and 2. Maximizing independence also helps relieve our family members and caregivers and enables them to pursue more of their own life activities.
- 4) GAIN AS MUCH KNOWLEDGE AS POSSIBLE: This one is critical to successfully deal with the prior three principles. There are two distinct components:
 - ❖ INSIDE KNOWLEDGE: This means knowing yourself thoroughly, especially the very specific aspects of your physical challenges including rates of deterioration in each affected body part. Although we may be getting assistance from experts, they are unlikely to be able to come up with a best fit solution for us unless we share our unique conditions with them.
 - ❖ OUTSIDE KNOWLEDGE: In order to find the best and most economical solutions for our physical issues, we need to first know what the options are, how they work, and what the costs are. New products are constantly being developed or improved, often with numerous variations in features. We need to be primarily responsible for knowing what is available by reading appropriate technical literature, such as *Quest Magazine* and *FSH WATCH*, and especially using online data sources. A major side benefit to online product research is that it almost always results in finding prices more favorable than local dealers.

Having a solid base of both inside and outside knowledge not only enables us to be more effective and efficient in finding helpful tools and solutions for the physical difficulties, but also provides a basis for

developing our own fixes or helpful support where generic solutions are inadequate or where solutions for our specific needs don't yet exist. When you have done your homework, you are better able to know what questions to ask and what answers are helpful.

What follows provides some of the experiences that have led me to the above principles.

(I) BACKGROUND AND PURPOSE

Since most of you with muscular dystrophy, particularly FSHD, are in earlier phases of it than I am, I'd like to share with you what I've learned through observations and research, but mostly trial and error that took into account some of my background in residential design and construction. I hope it will help you to build a knowledge base and help you avoid my mistakes to better deal with your individual challenges.

My name is Don Nemke and I'm 73 years old. I've had symptoms of FSH Muscular Dystrophy starting 60+ years ago and was formally diagnosed about 55 years ago. I'm currently in an advanced stage of FSHD and largely wheelchair-bound. The long lead time and slow progression of the disease enabled me to at least partially prepare for the physical deterioration, increasing daily challenges, and escalating financial demands.

All of us with muscular dystrophy have widely varying physical issues, complications, family and financial circumstances. My comments are biased toward my personal experience with the deterioration from FSHD and the modifications I've made to live as independently as possible. I hope you can use, modify, or extrapolate from my "solutions" to fit your unique situation so that you are able to anticipate and prepare for what you will face in the future.

If you have any questions, comments, or suggestions regarding the content, please don't hesitate to contact me at (520) 797-0771 or at DONNEMKE@AOL.COM.



(II) GENERAL OBSERVATIONS AND SUGGESTIONS

WAYS TO REDUCE COSTS OF HANDICAP RENOVATIONS, EQUIPMENT AND FURNISHINGS

- ❖ Overall having detailed and accurate information about your specific needs and the options available will greatly improve your chance of getting the optimum combination of a best fit solution and economy.
- ❖ Talk to other FSH Society and M.D.A. members that have experience dealing with the specific or similar issues. They likely will be the best informed, the most honest and helpful.
- ❖ Research online, preferably before talking to dealers and others to discover what options, features, and prices are available. Develop a specific product criteria list including the questions you need answered in order to determine which specific home improvement, product or model will best meet your needs.
- ❖ Research local contractors, dealers, your doctor and other health care people, and your insurance company keeping in mind that each has biases and/or limited information about your specific needs. Also, some manufacturers allow direct calls to their tech people to ask specific questions.
 - Contractors that specialize in aging-in-place improvements are most likely to have experience in handicap improvements and are more apt to be able to understand your specific needs. Local agencies dealing with the elderly or handicapped would likely know who these contractors are. However, if you don't live in a reasonably large urban area this source of help may not be readily available.
 - Insurance company business goal is to provide the simplest, low level customer solutions in order to minimize costs. You are likely to receive a mediocre generic solution instead of one that fully meets your individual needs. This can then necessitate your making equipment modifications if maximizing functionality and/or safety is a priority.
 - Doctors are familiar with which products are most likely to be approved by insurance. If you request an equipment prescription, make sure that the doctor is specific about your needs and requirements, especially if you need an upgrade from the basic level equipment. Also discuss your specific needs with the doctor before requesting a prescription.

Example: In late 2011 and early 2012 I was in a rehab facility recovering from a broken leg and wore a brace from my upper thigh to my ankle. When it was time to try standing and walking a few steps with a walker, the orthopedic doctor gave specific instructions to the physical therapy department and concluded with "And for safety, do not take the brace off during therapy". This is standard practice for broken leg recovery.

I told the doctor that my legs were very weak and I had minimal balance because of my muscular dystrophy. If my leg was locked in the brace I'd have to try stepping by throwing my leg out sideways in a peg-leg fashion. That movement plus the extra weight of the brace would pose an extreme risk of my losing balance and falling. Willing to listen and learn from a patient, the doctor amended his instructions to allow removal of the brace during therapy.

In this case the doctor's unfamiliarity with muscular dystrophy could have resulted in unnecessary risks if standard procedures had been followed. You know your body better than anyone. Be your own advocate.

Handicap equipment dealers can only have in stock a tiny fraction of available models and they usually stock the more basic ones that have the greatest likelihood of insurance approval. But the better, more professional dealers may have knowledge about the less generic and higher quality products, particularly if they have a well-seasoned staff that are or have been in rehabilitation functions.

- Call the manufacturer and talk to a technician to get more detailed answers and resolve questions.
- Test if possible. If models you are interested in, or reasonably close models are available at dealers, go test them and check all the key dimensions. This may change or confirm your criteria. Also, if possible, rent and test equipment in your home for a few days to confirm that it works for you.

EQUIPMENT AND FURNISHINGS MODIFICATIONS

It is not common to find equipment and furnishings that will meet all of your criteria. Thus, to improve the product functionality you need to often use some imagination to figure how to improve, modify or correct the deficiencies. Try to make any modifications flexible enough to accommodate additional future changes as your needs change. I've tried this numerous times with widely varying results but with an overall average outcome that was well worth the costs and extra effort.

TIME HORIZONS

Try to focus on your projected long term needs and goals when planning home furnishing and equipment improvements or renovations. Acting on short term needs can often result in having to invest more time and expense in future additional changes. I've made this mistake at least several times.

EXERCISING, PHYSICAL ACTIVITIES, WEIGHT CONTROL, AND SLEEP

The single biggest impact on safety is to reduce falling and related injury risks. I'm beyond the point of being able to do a wide range of physically demanding daily activities to keep in good shape. When I was still walking, including with a walker, I found that doing **daily stretching and exercising cut my falling rate**, mostly from collapsing knees, by at least 75%. I asked for and got good input from several rehabilitation specialists. When I skipped exercising for a while it became apparent because my joints would stiffen and I'd have less ability to perform daily functions in a stable manner. In short, I found daily exercising and stretching covering nearly all body movements and joints can compensate for the lack of vigorous physical activity. My biggest mistake to date has been the neglect of exercising during travel which resulted in an accident in 2011 which had serious financial consequences and more importantly, destroyed important parts of my mobility forever.

Recently (2018) for safety considerations, I discontinued walking and now use power wheelchairs for mobility and mechanical devices for transfer between various seating positions and locations.

When muscles are weakening, reducing body weight lessens the strain on overburdened muscles and helps extend mobility and other functions.

Try to always get a full night's sleep. I found inadequate sleep negatively impacts my ability to exercise to my full potential and noticeably reduces my stability in moving and overall stamina. Thus it increases physical risk.

NOW WHAT?

Now let's explore more specific issues and experiences that I hope might be of some value to you and help you bypass some of my mistakes.

(III) NEW HOME CONSTRUCTION AND MAJOR RENOVATION ISSUES AND IDEAS

BACKGROUND

Our current home was built in 1996 and included a number of handicap features specifically requested by me. Over the past 22 years there have been major renovations to flooring and several to the Master Bedroom and Bath to reflect my declining physical abilities and in some cases my prior mistakes in design features.

OUTDOORS AND ACCESS

LOT

Choose a flat lot to minimize driveway and sidewalk slopes which can become safety issues.

ENTRY DOOR/PRIMARY ACCESS

Recommend no steps with a concrete sidewalk sloped up flush to the door sill. There should be no extra costs and it will last forever. The alternative is to use a portable ramp attached to the door sill. It should be 36" wide (same as the door). You will have to modify/cut back part of the ramp side rail in order to have a functional screen door. The cost of a 36" portable ramp @ 2/2012 was approximately \$240 with online purchase. This was 20-30% less than local dealer bids.



SIDEWALKS

Recommend solid concrete with any inside corners poured at a 45° angle to lessen the sharpness of the corners. Unaltered inside corners are potential hazards to especially wheelchairs and scooters. Wheelchairs can easily tip over if a tire goes off the concrete. A scooter can get stuck due to the anti-tip wheels hanging up on the concrete as a rear wheel goes off the concrete.



A simple and inexpensive alternative is to add a 12"x12" or larger concrete or paving brick to the inside corners of the sidewalk.

If you live in a warmer climate, consider having concrete sidewalks, driveways, garage floor, and patio surfaces sealed with an elastic-type coating containing sand granules to prevent it from being slippery. This impervious coating protects the concrete from moisture, makes the surface very easy to clean, and collects less dirt so less dirt is tracked into the house.

ACCESS TO WATER FAUCETS, ELECTRICAL BOXES, IRRIGATION CONTROLS

Since this area has all the main utility lines coming in from the street, consider making the access from paving brick so it's easily removed and replaced when the major utility lines need repair or maintenance.

GARAGE TO HOUSE ACCESS

Recommend 36" wide portable ramp (probably 36" or 48" long) so it can be moved when needed. Various lengths are available including ones with handrails for additional stability. Recommend not using standard 30"-32" widths because they don't leave enough room for steering error for scooters or wheelchairs.



REAR HOUSE/PATIO ACCESS

Recommend concrete that's flat but raised to match the door sill. There should be no additional cost. A no-slope is safer and the concrete lasts forever. However, a negative is that there is no gap between the concrete surface and the start of the wall so invading termites and other insects can't be detected visually. This joint should be sprayed for termites, etc. more often than the rest of the home.



PATIO

Size

Consider widening the concrete since most patios are narrow and when furniture is added there's insufficient clearance for walkers, wheelchairs, etc. I recommend at least a 10 ft. minimum dimension. Consider adding space for a grill outside the roofed area. If you are active outdoors, you may want to consider further expanding the hard surface for greater yard use potential because traditional graveled areas or grass are much too dangerous to safely walk on, use a walker, wheelchair or scooter.



Door track and guide

The patio door track should be of rugged enough metal to not bend when heavy weight like a wheelchair plus passenger (400# - 600#) goes over it. Otherwise a thin rubber door sill wedge may be needed (check online). But with a wedge in place, any screen door in the adjacent door track won't be operable.

If the door track rail is aluminum (most likely) or a similar soft metal, there will be friction between it and the door rollers. This problem accelerates with the rapid wear of the rail with an end result that the door becomes very difficult to open and close, especially for someone with limited strength. The solution is to have a stainless steel snap-over rail put on the original rail and have the door rollers adjusted accordingly. This results in the door sliding much easier than the original equipment and it should last forever.



INTERIOR

Halls

Recommend 42" or greater to minimize wall damage, and to be able to accommodate the recommended interior door width of 32" plus its frame.

Doors

Basic

Ideally all interior doors, including bathrooms would be 36" wide to match the exterior doors. But they should be at least 32" wide. The door jamb takes up about 1" and the open door's width is about 1 ½ "so you lose about 2 ½ ". Thus, the net clearance/opening for a 32" door is only 29 ½ ". Most full-sized wheelchairs are 24"-26" wide. This leaves little margin for maneuvering error (below left).



Other considerations

Electronically operated interior doors should be considered if you're not able to easily open and close doors. This option also prevents the doors from getting damaged from foot and equipment contact.

Use pocket doors (below center) where possible as they have slightly more useable width and they're easier for someone with a walker or wheelchair to open and close. Also they won't get as banged up from foot or equipment contact.

Eliminate unnecessary doors for the same reasons, but consider noise and privacy issues before you make this decision.

Install lever/latch type door handles on all doors (below right).



FLOORING

Our house was built in 1996 with 50% tile and 50% commercial grade carpet. After I started using a wheelchair (about 6-8 years later) this was changed to 15% carpet (guest bedroom) 10% tile in the guest bath and Master Bath toilet areas, and 75% laminate flooring in the remainder of the house (partial mistake). I would strongly recommend tile in all bathroom areas because of the constant risk of water on the flooring. Textured vinyl would also work.

Carpet. Conventional carpet with long, soft fibers and soft under pad is the most dangerous for tripping and use of a walker. A motorized wheelchair will tear it up and grind in dirt. Recommend low, tight pile commercial grade carpet with no pad. It's firmer, safer and holds up better to heavy use. However, I'd recommend that no carpeting be used where there will be regular power wheelchair traffic.

Tile. Works very well as its firm, non-slippery (if properly chosen) and is very compatible with walkers and wheelchairs. Keeping the grout cleaned and sealed can be expensive, especially in kitchens.

Hardwood. It is firm, insulates well, is user friendly and can be refinished. It can be slippery for stocking feet unless there is a grain pattern. Also, some manufacturers will not provide a warranty if a full sized power wheelchair is on it because if the surface finish gets worn, a turning wheelchair can produce enough pressure to tear out the wood grain. Water spills and leaks can cause damage.

Laminate. It is installed with a very thin, firm rubber padding so it remains hard, yet insulates. It is harder and tougher than wood, but it can't be refinished and can be slippery unless a grainy surface is chosen. Water spills and leaks can cause damage.

Vinyl

I have no direct experience with it. It is inexpensive and easy to install, but damages more easily and can be slippery unless a non-smooth surface is chosen.

Concrete

I have no direct experience but this is beginning to catch on in many areas where there are no basements, as it is economical. The concrete is ground smooth and then sealed.



BATHROOMS

General

The Master bath should have sufficient open spots for turning radius of walkers and wheelchairs. (5 ft. recommended but can function down to 4 ft. if only smaller size wheelchairs will be used).

Use 17" tall toilets. Standard are 13" and 17".

Bathtub-Shower Combinations

Recommended if cost and space efficiency are important considerations. But, if a transfer bench will be used there will be considerable amounts of water getting onto the floor. Also, this choice may remove the future potential for converting to a roll-in shower.

- ❖ Use stainless steel screws to prevent rusting.
- ❖ Use only nickel plated or plastic grab bars to prevent rust.
- ❖ Portable plastic grab bars are also available if permanent ones are not feasible.
- ❖ Have multiple horizontal and vertical grab bars with two verticals above the entry point as this is the most dangerous loss of balance area.
- ❖ When stability or balance start becoming an issue, consider use of a transfer bench. These range from simple and inexpensive to more elaborate and easier to use. If a simple plastic bench is used, consider adding rubber or a soft top to ease sliding and improve comfort.



Separate shower

*First consideration should be given to a total prefab shower unit that includes floor, walls, seating, shelving/storage, plumbing fixtures, etc. They are much easier to install than construction from scratch and have minimal risk of leakage since there are few or no seams. However, it may be very difficult to match all of your design objectives especially to handle your specific physical deficiencies. If you're renovating an existing shower, you may not find a prefab that adequately fits your existing space/dimensions which can result in significantly escalated costs and complications from having to create new support walls and move existing plumbing and sewer lines.

*The other primary option is to build or renovate a shower from scratch to match all your functional requirements and feature preferences. The tradeoff is higher cost and a longer time to complete partially because all features and functions should be fully researched and the multiple parts will be from various sources, and may not initially work together.

*Make sure the shower area is large enough. I recommend a minimum of 20 sq. ft. to maximize interior design and equipment options and to easily accommodate roll-in type shower chairs or benches. This floor size or larger will also provide enough room for a shower assistant plus room for a conventional stand up shower. A roll-in option requires that there be no threshold at the entrance (i.e. must be flat). This is very simple but might leak more water onto adjacent flooring unless it is properly designed for roll-in use (see Subsequent Shower Renovation).

*An alternative is to have an adjustable height bench that extends to the shower curtain so you can get up and down off the bench with your feet outside the shower or you can use a board transfer device between a wheelchair and the bench. You also have the option to step into and out of the shower conventionally. This approach enables you to add a water-blocking strip at the shower entrance to eliminate water leakage onto adjacent flooring.

*Since I was still reasonably mobile at the time (1996) I had my home built with a separate shower containing a 22"W x 32"L x 24"H permanent marble bench. The large surface area and rigid nature of the bench made it excellent for shifting on it to easily bathe, and there was sufficient room so that all of the supporting materials were in easily accessible locations. A second hand-held type shower head was installed at the back of the bench. This is a nice feature, but my loss of arm strength prevented me from using it.

*Even though the caulking on the bench was closely monitored and regularly replaced, after 8 years a tiny leak developed allowing water inside the bench. After many months the water had rotted the wooden frame of the bench and water started leaking out under the shower floor tile and seeped under the bathroom flooring which was ruined. The flooring was replaced and the bench was rebuilt over a concrete block to prevent rotting. (Mistake)

*When I broke my leg in the fall of 2011, my knee was also damaged, making it less stable and not able to support much weight. To compensate, I needed to raise the height of the shower bench by about 2" so that I could safely sit and stand. Since the bench couldn't be economically raised, I

found a heavy duty 4' x 8' sheet of Plexiglas at Home Depot and had a frame and surface made of it to act as a topper to the existing bench. It contains a wider lip area toward the shower entrance to enable me the shower access alternative to get up and down to the topper from standing on the carpet pad outside the shower. It is light weight and easy to remove for cleaning. To make the bench top more comfortable to sit on, I have a sponge-type front door mat flipped upside down on the bench. Good for comfort, but it retains water so it molds easily, and requires periodic replacements.



*These experiences taught me that if I was redoing this bench concept from scratch I'd stick with a large bench top (2' x3') but I'd make it with adjustable height legs and a lightweight Plexiglas top so it can be easily cleaned and moved and it leaves open the future option of converting the shower to a roll-in type.

*The initial shower and bench design worked very effectively for over 20 years, but then using a walker became very difficult and too dangerous. This major ability change required a major shower renovation/redesign and other life style changes requiring different handicap equipment and support.

Subsequent Shower Renovation

*The inability to safely use a walker and at the same time extreme difficulty in showering myself required bathroom renovations, primarily with the shower area and function. Giving up using a walker required adapting to a device that could transfer me to and from the shower. I chose using a Sara lift type crane/lift to enable me to do transfers and get access to toilet functions, shower, bed, lift chairs and another wheelchair. In short, this was a major example of redesign/renovation to safely and functionally meet the ongoing changes due to FSHD. These changes occurred within the past year (2018).

*Since I now could no longer get access to the lift toilet, I had to switch to using a commode. To maximize the potential functions of the commode, I got one with locking wheels so that it could easily be moved into a shower and become a shower chair. An alternative would have been to get a portable shower bench and get access to it with the Sara lift. Either system requires a roll- in shower design with no access lip or transition strip. It must also be user friendly and safe for the shower giver to perform their functions.

*Showers with conventional shower drains have 4 slopes to the floor which makes access with anything with wheels difficult and unstable. A relatively new concept is a linear /strip drain which enables the floor to be a single and very mild slope. This also makes the floor safer for conventional shower users. One problem is that linear drains require modest modifications to the floor

design/framing and to the plumbing to gather the waste water. I found very few plumbers or renovation people that were experienced at working with this system.

*There are many types and sizes of tile for the flooring. The prior dominant variety was very small non-slip tiles. But they have lots of grout lines which need to be cleaned and resealed periodically. More recently much larger floor tiles have emerged that are more stable and have fewer grout lines to maintain. However, larger tile usually are more slippery and thus can be dangerous. With larger tiles, it is critical to find those with a non-slippery surface. To help with this search, there are now regulations that require many tiles to have a slippery rating. Obviously only those with a high rating should be considered. To confirm the non-slippery feature a couple pieces of tile should be felt and walked on with bare feet before making a purchase decision. Another major benefit of large size tile is that they can be used to build the shower walls and for the entire floor in the bathroom. This also makes the renovation job simpler. I used the large tile for all 3 of these areas. Using the large tile for the bathroom floor is safe against potential water damage and is easier to clean.

*This shower should also have a lower shower head with an extension hose to enable washing all parts of the person being bathed by another person. It should also have a standard height shower head for conventional stand-up showers.

*The shower depth should be at least 4 ½ feet to provide enough room for the bather and to enable the shower curtains to be closed. I only had 41" to work with so the curtains have to remain open and a large towel is placed along the shower entry to catch any water splashes.

*After the shower, the commode and I are dried then the commode is rolled out to where the Sara Lift can transfer me to the bed where I get dressed and do my daily exercises.



Sinks and counters

If space is available, install 2 sinks so one can be later modified while the other remains the traditional height for spouse/other use. Onset of wheelchair use will require cabinets to be removed from under a sink, the pipes wrapped with foam rubber to prevent knee damage and a thin, clear acrylic plate put on the bottom of the wall where the user's feet will be.



KITCHEN

We have made minimal modifications in this area as I am no longer the primary kitchen user. We do have all shelves under the lower cabinets and in the pantry on pull-out (sliding) rails to enable access to equipment with minimal need for bending or squatting.

Many special features are available for kitchens including elevating sinks and counter tops and upper shelves, special designed appliances, cutouts under counters for wheelchair users and others.



CLOSETS

*Make sure these are large enough for wheelchair access

*Use modular shelving design oriented and located to accommodate the needs of the disabled one. Adjust height of shelves and hanger bars (closet poles) for ease of use. Use adjustable design to more easily make modifications as needs change in the future.



INSURANCE ALERT

Check your home insurance carefully to determine if it will adequately cover your handicap improvements. Many insurance companies do not sufficiently cover these items or may require an additional premium to cover them.

If major handicap renovations or add-on improvements will be made, keep records and receipts and take photos to document. Store the information off-site to prevent fire and other damage to the records.

(IV) HOME FURNISHINGS

BACKGROUND

The following reflects my opinions and recommendations based on actual experience from using or testing various in-home improvements aimed at enhancing my safety, including reducing the number of falls and maximizing my functionality so that I can do more with a better net result.

FLOORING – SMALL AREA RUGS

Where non-carpet or non-tile flooring exists, small area rugs sized to support areas where standing or sitting movements are done can add to safety by reducing any chance of foot slippage – provided proper materials are used.

If a wheelchair is not yet being used, the thin, more rigid or dense kitchen type carpets can work if the back is painted with latex (Touchdown: 710 Kwik Seam Latex adhesive) to prevent slippage. Light, high pile bathroom type carpets are not safe because they're easy to trip on, the edges tend to curl and the rubberized bottom coating loses its grip with washing.

If a wheelchair is being used, it will move, turn, or jam the wheels when it passes over the above type carpets.

Rugs can be made from very dense, low pile commercial carpet which can be cut to appropriate sizes, have edging applied, and have the back painted with latex. These carpets are extremely stable even under wheelchair and walker wheels and will also last longer.



SEAT CUSHIONS

If your legs and back deteriorate sufficiently, you may need to add seat cushions to elevate the seating of chairs, etc. Seat cushions can also be used to modify the softness and shape of a seat to improve comfort.

Initially you likely will find workable solutions in standard cushions readily available at home furnishing stores. In order for the cushion to remain securely in place, it may be necessary to paint latex on the underside.



More advanced body deterioration may require cushions made specifically to solve your needs and properly fit your chair(s). Simpler custom-made cushions can be purchased from most upholstery stores.



Many varieties and options of seats for wheelchairs and scooters are available from dealers and online including some with gel packets to enable partial customizing of shape and support. The most sophisticated seat cushions can cost \$400-\$500. But even these seats tend to have generic design features that may not work for you. For example, most cushions are made to accommodate up to 300 pounds and if you weigh much less the cushion may be uncomfortably stiff. Most cushions are made for incontinence and have a plastic lining under the fabric outer layer which means the cushion surface has very little air circulation which can cause sweating and irritate skin. Also, if your buttocks do not conform to the typical shape, a standard seat will not provide uniform support across your entire contact area resulting in discomfort especially, after sitting for a long time.

Very complicated, multi-layered, body sculpted, very personalized cushions such as for wheelchairs can be partially developed by you with materials from fabric and upholstery supply shops and at a competitive price. You will need to research to find dealers or individuals who can work with you on this. Typically such cushions will

require much sturdier covering due to their more intense use and need to hold all the internal pieces together even if they're glued. Upholstery type fabric, while having more limited choices, works very well. An excellent maker of these type covers is someone specializing in auto and boat upholstery.

LIFT CHAIRS

These are automated recliners that also elevate to enable you to get up and down safely. The recliner feature also helps with blood circulation. There are a number of manufacturers, but two that dominate this product area. I have one from each and have had prior models also.

1. Pride is the best known and most widely available.

*It has by far the largest number of models with nearly all available in multiple sizes to best match your size. See www.pridemobility.com. Dealers usually stock only some of the more basic and best-selling models.

*The seat and back operate together as a single unit resulting in a limited number of positions. For me, the fully up position creates too steep of a seat slope and the back pushes me too far forward creating a safety hazard of falling forward. To compensate, I insert a wood rail under the front legs which lessens the seat angle to acceptable levels. Using wood rails under both front and back raises the entire seat height making it easier to get up and down.



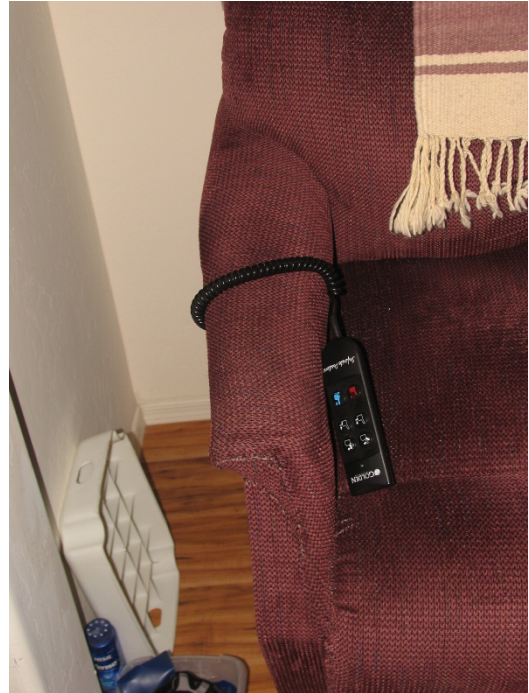
*Most handicap equipment dealers handle Pride chairs. Larger Walgreens stores now also carry them at very good prices (15%-40% less than dealer bids in 2/2012). Also check online for better pricing. If you buy online some assembly may be required and is not covered or available through the online sellers.

2. Golden is also widely available and I highly recommend them for their superior capability for infinite variable positioning.

*Their best feature is that the seat and back adjust separately so that position configurations are almost unlimited.

*The seating tends to be stiffer than Pride chairs. This problem may be reduced by adding a thin, soft custom sized foam cushion topper to the seat. Also there are fewer models to choose from than Pride.

*Few, but still multiple dealers, carry them including CVS pharmacies with home care departments. Also check online.



3. Other lift chair adjustments

When I was still mobile and using a walker, I could get into and out of the lift chairs but not safely. For stability, safety, and the need for a slight “push off”, I need to firmly grab the chair arm. This is impossible with nearly all models because the arm rests tend to be large and wide, very soft and/or slippery. I’m right side dominant so I had the right arm rest frame narrowed down to fit the size grip of my hand, had most of the soft stuffing removed, and had the fabric reattached. This enables me to firmly grab a totally stable support for my balance and “push off”.

As the body deteriorates, sitting in the lift chairs or recliners can become less comfortable and you may need to make additional chair adjustments to meet your specific needs. I made several simple modifications to offset the following problems. I hope this helps some of you to think about changes that can help with your specific challenges.

1) Seat Was Too Stiff. Standard seating is designed for users up to at least 300# and I’m less than ½ that. I got a 1” thick softer foam (from a foam and fabric store) cut to match the lift chair seat. The covering was custom made from very breathable fabric to minimize sweating and it had a zipper to allow for periodic removal for laundering.

2) Increasing Back Curvature and Need for Better Lumbar Support. Lumbar cushions can be found at wheelchair and Relax the Back stores but are limited in size and design. An alternative is to take several triangular pieces of Styrofoam and glue them together or use Velcro and then trim it to the proper size and best comfort. To cover and soften the rigid Styrofoam, a piece of soft 1” foam with a custom zip-off cover was used. The height of the foam was increased well above the Styrofoam wedge so that it could cushion my protruding shoulder blades, especially when in a reclined position.

3) Neck Pain. In addition to deteriorating neck muscles, I have serious neck arthritis which causes aches and pains. I found that a heating pad under the neck relieves the pain significantly. An electric mini-blanket was found online (Sunbeam for \$130). I chose a variable temperature control to give me maximum heat application options. The mini-blanket is good because it can be dropped down to also cover the back area. Also, if you have poor circulation resulting in chilled legs, the blanket can easily be moved to cover the legs. No automatic shut off is available, so care is needed to always turn off the blanket.



BEDS AND BEDDING

Beds

In addition to being comfortable should be of a height that's easy to get in and out of. Some considerations for adjusting the bed height are:

- Thicker mattress and box spring
- Mattress topper (3-4" thick)
- Wood frame riser made of 4-5 pieces of 2" x 4" x 8' lumber and laid into the existing metal bed frame. It raises the height by either 1 5/8" or 3 5/8" depending if you build it flat or edge up.
- A dual control air mattress allows softness for sleep comfort and when needed stiffens for easier and safer on-off access. I recommend Sleep Number Beds which has stores nationwide. Some bed models have the ability to adjust the mattress on each side separately to many different firmness and multiple contours. The ability to elevate the head and upper body can also help improve breathing and your oxygen intake efficiency and reduce snoring.

When your strength has decreased substantially, it may be difficult to move especially to roll over in bed. Switching to a **satin lower sheet** eliminates the "grabby" nature of standard cotton sheets.

Physical deterioration beyond this will likely require switching to a "hospital" type bed that has multiple adjustments and mattress options aimed specifically at handicap needs.

Pillows

Comfort considerations for neck muscle problems include special pillows to match your size and keep your neck level.

- A simple solution is to get foam of the right thickness and softness and have it cut to fit your pillow cases.
- A more elaborate and expensive solution is a pillow with 2 different size rolled edges that can better support both neck and head. These are available at [Relax the Back](#) and other bedding stores.
- If you have serious neck deterioration or pain, it may make sense to try building your own pillow using multiple foam layers with the stiffest layer on the bottom to hold the pillow shape and the softest layer on the top to easily conform to the shape of your face and neck. Make the edges square or near square not angular because then there is a larger surface area to support the weight of your head, thus reducing neck stress. This design feature also tends to hold your neck more in line with your spine. Make it a size and thickness that fits into a regular pillow case.

(V) SUPPORT EQUIPMENT AND HEALTH MONITORING DEVICES

WALKERS AND ROLLATORS

The equipment alternatives here most clearly show the differences between choices and the likely financial vs. functional trade-offs that a user needs to make. (Specifically, do you use insurance to get a very basic one or go direct pay and get something much safer and more functional. Maybe your insurance will pay the cost of the basic and allow you to pay the difference.)

Basic models cost about \$70.00. The user lifts it and moves it with each step or it may have two tiny wheels so it can be slid.

- It's very inexpensive, provides more arm exercise, is very light, folds up for easy storage and transport, is maintenance free, and is easily approved by insurance.
- But it is slow and more difficult to use thus actually discouraging walking. It's easy to trip on bumps such as door sills, flooring changes, carpeting, sidewalk cracks, etc.

Advanced models known as "Rollators" have 4 wheels, hand brakes, a seat, and a storage space. I recommend this version with the largest wheels available to maximize ease of use and safety while crossing rough spots.

- It rolls easily over carpet and small floor changes or bumps. The seat enables the user to rest. Also, if you or your arms get too tired you can sit and propel the walker with your feet. The seat and storage space enable the user to independently perform many daily functions by making it possible to carry laundry, dishes, etc. In short, its high functionality actually encourages more walking which should improve overall health and actually extend the time frame of the user's ability to walk.

- These rollators are available in several sizes and you need to try them to determine the best fit for you. I'm not tall, but for me the tall version is more functional. The seat height is 24" vs. 21" which enabled me to sit and get up more easily. When carrying things, the taller seat means I didn't have to bend over as far which is also safer. The wheel diameter is 8" vs. 6" which enables



the walker to go over rough spots more smoothly and safely. The larger wheel diameter requires less cable force for braking and thus the cables last longer.

There are two basic sub-types for rollators.

Light Weight Travel Friendly. This type has appeared in more recent years and is simpler and less expensive than more traditional rollators and is now the dominant product.

- Most are priced \$75-\$125
- Light weight and easy to store or travel with
- Storage is under the seat and is usually fabric
- More advanced versions have foldout foot supports so the user can be seated and have someone else push them similar to a manual wheelchair. But the costs are mostly \$125-\$175

Traditional Wire Basket Type

- Most prices range \$175-\$250
- Are heavier which makes them more stable to use over rougher areas (my opinion)
- Have a removable wire basket for storage which is much easier to access than the under seat storage. The basket corners can damage walls unless the corners are taped with soft material. The basket needs to be removed to fold the walker
- Are more difficult to store

ALTERNATIVES TO WALKERS FOR TRANSFERS

If your body deteriorates so using a walker or rollator becomes difficult and unsafe, it's time to consider a major life style change and a major piece of equipment that can transfer you to or between toilet, shower, bed, lift chair, wheelchair or other mobility device.

There are several types of crane-type devices that can perform these functions with the help of another person. I would recommend a version commonly referred to as a Sara Lift because it is specifically designed to lift you from a sitting position, elevate you to a fully standing position, move you, and then place you back into a sitting position. It has wheels and brakes and is very easy to operate, especially models where all functions except horizontal moving are electronically button controlled. Another nice feature of this type of lift is that when you are standing there are no restrictions on your middle body so someone can easily pull up or down your pants or undergarments.



In early 2018 I purchased a LIKO SABRINA II EE SIT TO STAND POWER PATIENT LIFT. The parent company is Hill-Rom which specializes in hospital beds and related equipment. The price was \$4750 which I found online at MEDICAL SHOP and that was about \$400 less expensive than buying from the manufacturer. For easier and smoother rolling, I later bought larger wheels (\$330). To provide for additional support for when my standing ability declines, I bought an additional support strap assembly (\$470).

A nice plus is that since the manufacturer, Hill Rom, sells lots of equipment to local healthcare facilities, hospitals, and nursing homes, it has tech support in most major urban areas. They provide product assembly, adjustment for your specific dimensions and any subsequent repairs or modifications.

So far this product works great and is far safer for me than using a walker. It requires flat floors with very minor flooring transition strips primarily because it has very small caster wheels which are necessary to get the horizontal legs under low clearances such as beds -- in order to pick up or deposit a person.



BATHROOM TOILETS AND ACCESSORIES

Toilet heights are standard at 13" and 17" plus the seat. Most toilets are built with the 13" version which can be too low as we age and/or lose muscles. A typical sequence of improvements as a person's abilities deteriorate is as follows:

- Add horizontal grab bars to lift or push off from the toilet and vertical grab bars for balance while standing.
- Add a 4"-5" plastic topper to the toilet bringing the height to 17"-18".
- Replace the 13" toilet with a 17" and add the topper bringing the height to 21"-22". Now you've exhausted the standard solutions.



A more advanced solution was developed that has a much larger (almost infinite) range of heights that can take you up to a standing position. It is a mechanical toilet seat lift operating on electricity with a button control. It's made by **Stand Aide of Iowa**. It can be placed over any toilet including the 13". It has arms which greatly reduces or eliminates the need for horizontal grab bars. My cost to install one about 6 years ago was \$1500.00 including bringing in an electrical outlet which was not available near my toilet. For more comfort I'd recommend replacing a standard seat with a padded one. These cost about \$30.00 and are readily available in hardware and plumbing stores. I strongly recommend considering this very safe option. The battery and charging mechanism lasted over 5 years and its replacement cost was \$625.00. Regardless of the type of toilet, always have a rug for the foot area that is low pile, very firm and has a painted-on latex backing so that it can't slip on the floor under the extreme pressure it must endure.



COMMUNE – A TOILET ALTERNATIVE AND MORE

If or when bodily functions make it too dangerous or difficult to use a walker, it may be unsafe to use a conventional toilet. Also, if you choose or need to use a Sara Lift or similar crane device to make transfers to your toilet facility you should consider a commode. It can be placed almost anywhere in the bathroom to maximize accessibility. There are many versions available online. I'd recommend the following features to maximize functionality and your safety.

- Wheels. This enables the commode to easily be moved with you on it including the ability to roll it into the shower to use it as a shower chair.
- Locking Wheels. This keeps it from moving when you're getting on or off.
- Padded Seat. For greater comfort.
- Proper Height. The tallest commodes can be backed over a conventional toilet so that the waste bucket isn't needed and all other conventional toilet functions are usable. The measurement of the height of the existing toilet is critical since most commodes are not tall enough to fit over a 17" toilet but will fit the shorter 13" version.
- 5) Modifications. If the commode will also be used as a shower chair, you may want to consider removing the backrest so that your back can be washed more easily. However, if you have poor balance while sitting or being moved on the commode, it could cause an increased risk of loss of balance.



Commodes are readily available online. A year ago I purchased one with all the above recommended features. It is a Nova Shower Chair/Commode – Model 8800 for \$162.

Currently I would not recommend this model because of a couple of mechanical failures that recently occurred after only several months of daily use. Nova has been very responsive and has sent me free replacement parts. However, it will take me at least several more months to test the replacement parts to determine whether the 2 problems are design flaws affecting all units or just an assemble or similar problem that impacted only my unit.

HEALTH MONITORING DEVICES

A few years ago my neurologist informed me that FSHD, particularly with advanced deterioration like mine, could cause breathing problems, especially at night, and heart function irregularities. She arranged for me to have tests and recommended that I have these tests repeated periodically to monitor whether the breathing and heart functions were deteriorating and getting to where medical solutions were needed. To her credit she also told me that monitoring devices were available online.

Breathing/Oxygen Intake/Pulse

The primary concern for breathing is to have adequate oxygen intake efficiency which is vital for many body and mental functions. The pulse involves heart rate, intensity and rhythm pattern which also affects many body parts. If you observe you will notice that these two functions are checked as part of your vital statistics taken during your doctors' appointments.

To test these items overnight requires wearing a Pulse-Oximeter which is like a large wrist watch with a wired connection to a device that's put over the end of a finger to capture the data. The watch face shows the oxygen intake efficiency figure, the heart rate and a "moving graph" showing the patterns, intensity and irregularities of the heartbeat.



The device has the ability to store all the details overnight so that it can be connected to a computer the next day to analyze the data, issue a summary report and also a minute-by-minute graph of the heart rate and oxygen intake. The Pulse-Oximeter can also be attached for several minutes during the day to see current functions. There are specific guidelines for the minimum oxygen intake function for day and night.

Rather than have these expensive tests done periodically by others, I recommend you purchase your own Pulse-Oximeter which includes the analytical software for the computer. I found it online at Clinical Guard for about \$120.

My first test was done overnight professionally and showed a number of night periods where the oxygen intake was below minimum standards which could cause longer term health problems. Therefore I wanted to be able to experiment and test at will to try to solve the problem. After only several more tests by me, most of the substandard oxygen intake was eliminated. The partial solution was that I could breathe better through one nostril so I trained myself to eliminate all sleep positions that relied on the less efficient nostril. I suspect that I could also improve the oxygen intake by sleeping on a wedge or a bed that could elevate the upper body.

The bottom line is that this monitoring device is a simple and inexpensive way to monitor a couple of body functions and to enable non-medical experimentation to try to solve deficiencies. Test results should be shared with appropriate physicians.

Blood Pressure Monitors

This one is much simpler. They are very inexpensive (\$30-\$100) and are widely available at drug stores, medical shops, and online.

There are standards for acceptable blood pressure ranges. The blood pressure should be checked periodically and recorded in a file so that any trends can easily be detected. Unusual figures should be retested for any errors and, if confirmed, should be reported to the appropriate physician.



Overview

Self-monitoring devices, including a stethoscope, should be considered because they can improve the prospect of improved long term health by detecting potential problems at an earlier stage.

For example, I was given a prescription which made huge changes to my heart beat and blood pressure. After several days of consistently bad numbers, I notified my physician. He had me immediately stop using the prescription because of high risks from the bad side effects.

Recently my heart rhythm has been getting more irregular which prompted me to do tests more frequently and keep more detailed records to provide a medical data base for a physician to determine higher risk patterns should they develop.

(VI) MOBILITY EQUIPMENT AND SUPPORT

OVERVIEW

If you are limited to only one mobility device, my recommendation for the best all-around functionality for most people would be a full-sized wheelchair with a removable backpack for carrying items.

MANUAL WHEELCHAIRS

I have no direct experience but I have several observations. The largest maker of these is Invacare and this brand is dominant in most hospitals, nursing homes, retirement centers, etc.

*These devices are inexpensive, light, and collapsible for easy travel; provide good exercise to arms and shoulders and multiple models are on display at a wide range of dealers. They can also be propelled by using the feet.

*But the user must have strong arms and upper body and/or strong legs which is not common with many people with M.D. It is also more limited for longer-range distances, especially outdoors.

ELECTRICAL WHEELCHAIRS – MINIATURES

I have not operated one of these but from examining them I have the following comments:

*These are much less expensive, are easier to get insurance coverage for, have small turning radiuses making them easier to use in tight spaces and homes, are lighter to transport, require less expensive lifts and vehicle modifications, and have less negative impact on flooring, walls, etc.

*But the compact size makes them more suited for smaller people, they are slower and have small tires making them not as safe and not well suited for outdoor use, they offer only a limited number of options making them less or non-functional for many activities and daily functions especially for those with more severe physical limitations such as those needing an elevating seat, special leg supports, sophisticated seating, etc.

*These types of wheelchairs are best suited for those whose physical deterioration has not yet gotten substantial.

ELECTRICAL WHEELCHAIRS – FULL SIZE

These chairs usually weigh 400-600 pounds with the person on them. They offer endless options to enable them to closely fit most people's needs. The biggest brand names, Pride and Invacare, are available through many sources, and they both have a large number of models. In recent years there have been many more brands readily available like Permobil, and Quantum. They travel at 5 MPH or more with a typical distance capacity (when in good condition) of 15-20 miles and with a large base they are able to handle rougher terrain and thus are well suited for outdoor use. However, their heavy weight can be hard on flooring and the larger turning radius can restrict some indoor uses and

can cause more damage to walls, doors, etc. They also require heavy duty type lifts or cranes for transport and likely require suspension strengthening or modifications for the transporting vehicles if the lift is external.

When considering a wheelchair, I'd strongly recommend one where the drive wheels are centered front-to-back. It is easier and safer to maneuver in tight spaces and will result in less damage to walls and furniture.

Because of their extreme weight and knobby tires, chairs pick up lots of dirt on the tires like blacktop tar which is then transferred onto house flooring, especially carpet, unless the tires are cleaned before going indoors. Wet and dry towels, driven over in circles can remove most of the dirt.



Because this equipment is very complicated, with many options and many sophisticated parts, I would recommend giving first preference to the biggest brand names because their available technical information for making choices is very good and dealers with access to parts are much more numerous in case of mechanical problems. However, there are much better and more sophisticated chairs such as Permobil.

The first chair I had was a Pride and then I got an Invacare. Currently a Permobil is my primary chair with the Invacare as a backup. A comparison of all three wheelchairs may shed light on the types of specific considerations and technical data needed when shopping and will show examples of potential problems.

Pride – Jazzy 1122, Cost \$6000.00-\$7000.00 about 15 years ago. It's a very simple model, but I kept it as a backup for a newer Invacare chair because I couldn't find rentals that have an elevating seat which I needed. Also the seat back has a wide range of user-controlled adjustment angles making it very comfortable for reading, relaxing, etc.



Features/Options

*Captain's chair type with a cloth seat which included cloth-covered arm rests and a fold back controller. The cloth appears to be similar to auto upholstery and is very durable and it doesn't cause sweating. The seat cushion is permanently attached so it can't be swapped out.

*Base includes an on-board charger.

*Flip up arm rests and a swiveling seat which increase on/off access options.

*Special attachments were added to the frame to enable it to be attached to a crane.

Problems/Surprises

*The permanently attached seat cushion is a negative because you can't swap cushions to better accommodate changing body conditions.

*Because the elevating seat was a new and rare feature back then, there was no detailed data on how it impacted chair dimensions. Upon delivery I found the elevating seat sits 1 ½ " higher than the normal seat, thus raising my knees and legs so they no longer fit under a standard height dining table, my work desk, or bathroom sink. The dealer was a good engineer. He cut the chair frame from the main frame, lowered it 1" and re-welded it to the main frame. Problem solved—but warranty invalidated and there is less clearance under the chair.

*Toggle switch for the elevating seat was too small and located along the side of the seat where leg movement and getting in and out of the chair on that side could trigger the switch. The dealer installed a much more functional version at a safer location.

*In 2008 when researching for a new ramp van (including renting one for a couple days) I found the chair didn't have and couldn't get solid or safe floor tie downs. Its turning radius was too big to easily turn around inside the van. Thus, a different, more compatible chair was needed for the new van.

*A fold back type controller is a necessary option so the controller can pull back to about the end of the armrest. Without this option, the wheelchair can't get close enough to a table, desk, sink, etc. Some models of fold back still stick out ahead of the armrest thus potentially limiting the ability to get close enough and raising the risk of the controls getting damaged by hitting something. This option needs to be checked closely for any chairs being considered.



Invacare – TDX SP. Cost \$12,000.00 about 10 years ago. The base is a standard Invacare model. But to maximize the fit to my conditions, I worked with Motion Concepts, an Invacare subsidiary that specializes in seating options. Every piece of seating feature had to be individually selected and needed to be carefully researched and coordinated with other parts to work properly.

Features/Options

*6 vs. 4 wheels on the ground, thus more stability.

*Tie down hooks on all four corners.

*Reclining backrest but with limited adjustments. Adjustments lever is on the back of the seat so changes must be made by someone other than the wheelchair user which is a major inconvenience.

*Adjustable seat pan base so seat cushions of slightly different sizes, shapes and thicknesses could be removed or added easily. This enables me to accommodate my changing needs. The pan base also can be slightly position adjusted.

*Headrest had multiple adjustment options so it could be exactly matched to conform to the user's head and neck. (Pride headrest had only 3 height adjustment options).

*Off board charger. No onboard option making it more inconvenient and bothersome to charge.

*Vinyl covered arm rests; easily removable so damaged ones can be replaced.

*Drop down panels from arm rest to seat bottom has small storage pockets. Also, the dropdown was adjusted tight to the side of the seat enabling things to be carried between the side of the legs and drop down panel.

* Fold back controller.

Problems/Surprises

*The headrest adjust mechanism had a metal post sticking out horizontally well beyond the rest of the chair back. In public places, people would frequently bump into it. Making turns or backing too close to a wall could cause serious gouges or damage. To position the wheelchair in the van I back the wheelchair toward a side window and the post would regularly hit the



window. I had the post sawed off and glued a leather piece to the exposed end thus solving all 3 problems.

*The upholstery was very thin and wore out quickly. I had to have the whole seat system reupholstered by an auto and boat upholsterer. They used a much heavier auto fabric.

*The biggest problem was that while the engineering and functionality are excellent, the manufacturing was terrible. This resulted in replacement of almost all major parts (both motors, seat elevator twice, rear caster bearings three times). This obviously was very expensive and inconvenient. For the last set of problems the dealer was able to get Invacare to replace the entire base of the chair at no charge. Since then it is working fine.

I kept this wheelchair as a backup when I bought another chair in 2015. Since it's smaller and more agile than the newer chair, it gets used for most out-of-home activities.

If you deteriorate substantially you may need to upgrade to a much more sophisticated wheelchair with considerably more options in order to adequately meet your needs.

About 4-5 years ago my neck and back had substantially deteriorated with increasing aches and pains especially upon movements. Thus I needed much more versatile and capable wheelchair seating to remain comfortable and functional as possible. I researched all wheelchair options, mostly online, but also at several wheelchair dealers. At that time the Permobil brand appeared to be the best overall fit.

Permobile – M300 Corpus 3G

The list price including my best fit options was \$35,000. The best dealer bid was \$27,000. Then I got lucky. One bidder who had their primary facility in a nearby larger urban area had a recently deceased customer who had a one year old Permobile that was the specific model I was looking for. I tested it and bought it from the family of the deceased in 2015. All the seating and controls needed to be totally replaced to fit my needs. It took lots of research and purchase of items from many sources and substantial work and some innovation to get all parts working together properly. The project took about 5 months to complete with a total cost of the chair and changes was about \$15,000. This exercise confirmed that for major handicap equipment it makes sense to spend time and effort to find used items that are still in acceptable condition and at bargain prices.



Features/Options

- *Seat pan that elevates and can tilt both forward and backward electronically into almost limitless positions
- *Adjustable seat pan base that can accommodate different size seat cushions that can easily be attached by using Velcro on both the pan and cushion bottom
- *Leg support/foot plate that can tilt electronically to a wide range of positions which is helpful if poor circulation requires elevated leg positions periodically or constantly
- *Seat back that can adjust electronically from a slight forward position to a fully reclined backward position
- *Control box with buttons to control each of the above movements. All movements are available simultaneously and together can create limitless seating and support positions exceeding the capabilities of the most sophisticated type recliner or lift chair.

For me this is the most critical feature because the deteriorating neck, back and leg circulation require several periods daily where I have to recline to a zero-gravity position. This also provides for the ability to comfortably nap. To make the back comfortable I had a custom lumbar support inserted to the lower seat and had a soft foam fabric pad made covering the whole back in order to cushion my protruding shoulder blades when I'm in a recline position.

*Far more speed options (10) than usual at a top speed much faster than nearly any other wheelchair or scooter which makes it attractive for longer distance outdoor use.

*6 wheels on the ground for good stability. I opted to use the smaller caster wheel option to reduce the risk of the wheels hitting my feet if they might be slightly beyond the side of the footplate. When very tight turns were made the caster wheels faced the footplate with very little clearance for foot placement error

*Tie down loops on all four corners

*Head rest with a wide range of height and angle adjustments

*Off board charger

*Flip up armrests for easy transfers onto and off the seat

*Fold back controller

*Wide range of forward/backward adjustments for the armrests

*Almost limitless seating types and seat cushions.



Problems/Surprises

*The chair seat cushion is taller than most making it a tighter fit to get the user's legs under tables, desks, sinks. Most require the seat to be tilted down on the forward side in order to achieve adequate knee and leg clearance

*It's larger than most chairs and doesn't have as small of a turning radius making it more challenging and risky to maneuver in limited spaces

*If the electronic seat adjustment options are used many times during the day, which I do, it drains the batteries more rapidly requiring daily charging and this reduces the battery life to 1-2 years at a cost of \$400-\$700

*To operate the seat elevation and any other functions the chair has to be turned on. All controls are in one tight location—right hand for me. To transfer to the driver's seat in the van required transfer onto and off of the left side of the wheelchair seat. Thus I had to have duplicate on/off and seat elevation controls mounted on the left side of the chair so I could reach them from the van driver's seat.

SCOOTERS – COMPACT

I have not tested one but my sister with FSHD has one and I've been able to see its features and operation. These have a good range of functionality for less intensive type users who don't require special features.

*They cost less, are maneuverable enough for indoor use, and have enough endurance for trips of several miles. A few models like Pride Go-Go break apart into several pieces and fold so they can easily be transported, even on airplanes, and quickly reassembled for use. The pieces are light enough that a lift or modification to vehicle suspension is not required.

*But they are sized for smaller people without serious limitations, have small tires so they could get stuck easily, and they have limited options.

SCOOTERS –FULL SIZE

These are primarily for outdoor use and can almost function like a second vehicle as they have good range of 15-20 miles. These have significant carrying capacity with the basket, floor, and potential for a large seat backpack. They usually have an option to enable them to haul a walker on the back thus greatly increasing functionality. But with this option adding a backpack is not possible. There are enough options for most people. I initially had a 3-wheeler (Pride). Then I got a 4-wheeler (Pace Saver) which I had for about 15 years. Recently I gave the scooter away because my deteriorating neck and back created too much discomfort and aches while trying to drive it.

3-Wheeler

*They are lighter, easier to steer and have more foot space.

*But it is not real stable on rougher terrain and gets stuck very easily if driven off hard surfaces. This safety hazard is why I switched to a 4-wheeler.

4-Wheeler

*They are very stable on rougher terrain and much less likely to get stuck, but softer soil or gravel should still be avoided.

*But they are less maneuverable, harder to steer, and have less foot room.

Note: I used my 4-wheel scooter as a second vehicle for 4-5 years because we only had one vehicle and my wife still worked. I made multiple weekly 3 mile trips to local stores and the library and occasionally to a larger shopping center about 10-12 miles round trip. It was used on trails and locally to accompany my wife on walks through various scenic areas. I estimate that I logged over 2,000 miles on this scooter.



LEG BRACES AND SHOES

As foot muscles deteriorate, it will usually result in toe drop which is a risk for tripping and falling. The ankles begin curving inward which causes feet to not hit the floor flat and firm when stepping. Lower leg braces can solve both problems if they are properly designed to meet your specific conditions. Making this happen can take considerable time, patience and input on your part.

Example: To reduce my fall rate, I attempted to solve my toe drop/tripping by going to a local brace maker. In addition to addressing toe drop, I explicitly requested some ankle flexibility so that I could continue my walking and driving. The end result was a single piece of form-fitting plastic that solved the toe drop but made it impossible to walk on any slopes or to drive. Thus, the solution was totally non-functional. I was discouraged and quit pursuing braces.

My sister, who lives in another state, also has FSHD. She asked her brace specialist if he knew of reputable counterparts in my area. He did and I was able to track one down. This person only needed about 10 seconds of time to see me walk just several steps to know what was needed. The end result was a pair of very functional braces.

This experience reinforced the observation that all highly qualified professionals are not equal in their ability to diagnose special needs and develop satisfactory solutions. It also taught me to not give up on pursuing workable solutions to my physical shortcomings.

The design of shoes, especially the soles can impact safety via toe stubbing potential and firmness of balance. The material used (leather vs. fabric) can impact foot swelling and comfort. Newer materials, particularly in athletic shoes, can greatly reduce shoe weight and thus the effort needed to walk or perform other activities like driving.

I found that braces in conjunction with lighter weight shoes enabled me to safely continue walking mostly with a walker. However, after a number of years of deterioration in muscles combined with reduced walking and other physical activities I developed increasingly poor blood circulation primarily in the lower legs. This led to easy chilling in the legs and rapidly growing problems of severe foot swelling when shoes are worn for more than a couple hours. To reduce the foot swelling to a minor issue, I converted to oversized shoes. These however, are loose and sloppy, greatly increasing instability in walking. Due to the escalated risks, my walking in shoes with a walker was over in 2016. Since then I only wear socks. To minimize the risks of my feet slipping on the floor, I mostly used medical socks by McKesson that have non-slip bottoms. Since I totally quit walking in 2018 I now have more options to use non-medical socks as well.

VII TRAVELING

BY VEHICLE

We traveled extensively during 2000-2016; all by minivan. My experience is limited to 3 minivans, with interior lifts and currently a conversion ramp van.

Vans with interior lift

I chose interior crane-type lifts to enable travel in rain, sun and on dusty roads. This version is simple and relatively inexpensive because it usually only requires removing the rear seating and installing an electronic crane. It will also require removing the spare tire if it is located inside instead of under the van. If so, then for safety, you should switch to run-flat tires. They generally worked well. A safety suggestion would be to use snaps rather than open hooks to attach to what you're lifting and periodically examine the lift cable for wear as it can break with very little wear showing. This happened once while traveling. Thankfully, it only fell a few inches, with no damage or injury.

These lifts require two people to safely operate which is very inefficient for errands and other short trips. It also requires that the person with MD be able to walk between the van seat and the tailgate. When I lost the ability to safely walk (2008), we switched to a conversion ramp van. There are many versions of ramp vans with models available to inspect and test at handicap vehicle dealers. However, you may have to travel to a larger urban area to be able to see adequate alternatives.

Van with in-floor side ramp

We chose this option in a 2008 Toyota Sienna. No walking is required because the chair is driven into the van; the driver's seat comes back on a track so you can slide into the driver's seat. No second person is required so it releases the other person to pursue their own schedule. Thus it gives the disabled person full independence to do their own errands, shopping, etc. At this point I've had this vehicle over 10 years with 160,000 miles and am very satisfied with how it works. I don't use any special driving controls and have driven long distances frequently.

By 2018 my physical decline was significantly increasing the safety hazards and was getting difficult. I opted to quit driving altogether although I could still drive in an emergency.

Insurance Alert. If you have major costly handicap improvements on your vehicle, check your insurance coverage carefully. Many insurance companies do not adequately cover these improvements. They may require higher premiums to cover them. Also, keep records and receipts for all major improvements.



OTHER EQUIPMENT TO SUPPORT TRAVELLING

If you use a wheelchair or scooter, in order to be able to travel easily and comfortably by motor vehicle, several pieces of equipment may be needed. Also you should book handicap accessible hotel rooms which are better designed to handle your needs.

*A portable ramp is necessary even if you don't travel because it enables access to other people's homes and to older businesses, stores, etc. that have entry steps.

*A 4" plastic topper for a toilet is needed if getting up and down is a problem.



*A portable height-adjustable transfer bench is advisable for safety, as motels carry only compact, limited use bath chairs or have a fixed location dropdown bench on the shower wall.

*A portable suction-type grab bar is advisable as many bathrooms have inadequate or no grab bars.



In addition to the above, it may be necessary to modify vehicle seating to make long distance travel comfortable.

Modifications will typically become more extensive as physical conditions deteriorate. I went through the following sequence:

*Added a mesh coated wire seat and back cushion to offset problems of sweating and shoulder blades sticking out and rubbing the seat back.

*When the wire became too stiff to sit on, I switched to a soft foam seat and back.

*When my back deteriorated and changed shape, I needed special lumbar support. I found a back piece with an adjustable lumbar support plus a comfortable form-fitting seat cushion at [Relax the Back](#). This seat improvement extended my ability to travel long distances by at least several years.



AIR TRAVEL

For air travel while using a wheelchair I strongly suggest going online to www.FSHSOCIETY.ORG/library and read the article written by Howard Chabner entitled *Tips for Air Travel with a Power Wheelchair*.