

Living In an ADA World

I have IBMPFD, a genetic disease covered by the MDA. The symptoms include adult onset muscle atrophy then possibly Paget disease and fronto-temporal dementia. As with most genetic diseases, there are no known treatments or cures. Since this is adult onset, I have had to continuously learn how to adjust my life to compensate for the loss of muscle.

My wife and I have always enjoyed traveling, so even after I retired we are still attempting to travel, sometimes in our motor home (which has been significantly customized), sometimes staying in motels. We often eat out, sometimes fast food, sometimes in local restaurants. We have traveled to several university research locations around the USA that are attempting to learn more about IBMPFD, along with trying to find some treatments. Thus, we have gained a lot of knowledge about what is available and what we need to do for ourselves

Since I became noticeably affected after the passage of ADA (Americans with Disability Act), I am very unfamiliar with conditions prior to implementation, but I think the ADA has significantly helped, although there are of course, limitations. There are two major reasons that will limit any legislation to help those of us with mobility impairments:

1. The wide variation in types of impairments, e.g., even though my brother and I have the same mutation, we are affected differently so need different aids at different times and locations.
2. The wide variation in the physical size and needs of those impaired, e.g., even though my sister and I have the same mutation, we are significantly different in height and weight, along with the different needs of the two genders.

Therefore, one would be unreasonable to expect that the ADA or any other well-intended business, individual, or legislation could completely satisfy his or her own needs. Each of us must be prepared both to deal with lack of aids by using our own items that fit our specific needs, as well as educating those that would like to help on what best to do.

There are two major locations of concern for the mobility impaired:

1. How to get around one's own residence?
2. How to get around when traveling, whether on vacation or just shopping?

Another issue of concern is how will the caregivers be able to deal with both the physical and mental problems associated with caring for a physically and eventually mentally impaired person? When designing or modifying locations or using aids for the impaired, one must also consider the needs of the caregiver.

The following will offer some suggestions that we have found that help, both in modifying our home to accommodate our needs as well as when traveling. Not all suggestions will be applicable to all users, but some may help or give ideas for something else.

For the Home

The information about a residence assumes one owns one's home. There are additional issues to be addressed if one must deal with a landlord, this article does not address those issues. There are also potentially issues with building codes and inspectors that can cause both irritations and delays in making changes.

When building or modifying a home for the mobility impaired, there are a lot of resources that provide information suitable for the "average" individual (I am not sure what the average is in terms of impairment or size as far as either the medical or government community defines, but I definitely do not fit their profile). A significant number of architectural and construction firms are absolutely "clueless" regarding implementation of aids for the mobility impaired or the ADA rules, much less implementing them in a useful fashion. Thus, one must be prepared to not only find someone knowledgeable in the field, but also one must be prepared to provide significant input and review about one's own requirements and needs.

The ADA does provide a CD (see www.ada.gov) that includes a lot of information about all ADA topics (although written in governmentese so difficult to wade through). The rules and guidelines clearly illustrate the minimum required to help certain impairments for a limited size range. The problem is the **cost** of implementing standards that would apply to a wider range of sizes and impairments. There is a lot of very good information in the CD, which (more-or-less) clearly shows what regulations are applied to commercial establishments. For example, there is a check list (40+ pages) for various items; if one is not satisfied with handicap accessibility implementation at a location, fill out the check list and send to the appropriate local government authority and that establishment.

I designed an addition for our house to accommodate my increasing immobility. (By intent we live in an area with no building codes or inspectors, so we can meet or exceed as desired NEC and other safety requirements without lengthy explanations, but that also means there are no architects or other resources; thus, I had both the freedom and necessity to learn and do what is required for my needs) I used the rules from the ADA (on the CD, e.g., a 92 page document) to help design the size of doors, halls, rooms; the location of toilets, showers, sinks; the angle and with of ramps and entryways; the location of lights, fans, switches, outlets, and other electrical equipment. The addition was also designed for solar heating and very high-energy efficiency. However, I could not just show the rules to the contractor (who is very experienced and very willing to do what makes sense); I had to "translate" them into working dimensions in the drawings for the addition. Of course, the house does not follow the existing rules exactly; I had to have dimensions to match my size (I am significantly taller than the ADA average and somewhat heavier).

Making improvements and changes will be more difficult in urban areas where excessive regulations and bureaucracy impede the customization required for the mobility impaired (as well as those larger/smaller than normal). That means one must start to work with

both the licensing areas and the inspectors early in the modification process and make sure one has a good understanding of why the modifications that are necessary may require slightly different interpretations of existing rules or precedents.

Specific recommendations for buildings include:

1. Make hallways or other walkways even wider than recommended, e.g., at least 4 feet. That way turns are easier as well as easing the work of the person pushing the wheel chair or transportation device.
2. All doorways should be at least 3 feet wide, preferably 3 ½ feet wide.
3. Showers should be “roll-in” and large enough to easily push a wheelchair around in, including leaving space for the person pushing the wheel chair.
4. Counters and other work surfaces should be at the height of the person using them, usually meaning higher or lower than normal.
5. Ramps should be used over grades, no steeper than 1 in 12.
6. Thresholds should have non-vertical surfaces to prevent tripping and to ease passage of wheeled aids.
7. Light switches and other electrical controls should be at convenient heights.
8. Communication lines, whether cable, phone, intercom, Ethernet, or entertainment should be pre-wired for accessibility

When Traveling

While the ADA has made getting about a lot easier for many mobility impaired people and their caregivers, there are still a lot of things that we must do and take responsibility for in order to improve our traveling experiences.

When traveling, we must recognize that the rest of society will not readily provide the infrastructure (at significant cost) to make all things convenient or comfortable for all of us with different impairments or larger/smaller than "average". For example, having "adjustable height western-king" beds in motels would be great, but is probably cost prohibitive. There is also the problem of bed size, e.g., some of us cannot lay flat on an 80" bed, we must be at an angle so that all of us are on the bed. We must learn to be proactive in obtaining a suitable comfort level, while trying to constructively deal with existing impediments, i.e., if you will not or cannot invest in the aids for your own comfort and convenience, do not complain that others did not gladly do so.

Most people you meet will help where they can, but the management of organizations that must fund the equipment and installation are still responsible to their shareholders that any investments have an adequate cost/benefit ratio. While regulations over rule these financial considerations, education that there is a sufficiently large mobility impaired population that will utilize the facilities would go a lot further in spreading implementation, e.g., better handicap accessible rooms have a higher occupancy ratio than either regular rooms or handicap rooms that are poorly done, so a better return on investment.

The following are suggestions that we have found to both help us, as well as encourage those that want to improve (but do not know what or how):

1. Remember to carry a "booster seat" for all those low toilets.
2. Remember to carry a walker or multiple-point cane for all those bathrooms that do not have grab bars in useful locations, e.g., near showers.
3. Always ask managers of motels/hotels for extra bath mats, both for the bathroom floor and the tub/shower floor to minimize slippage (on tile that gets slick when wet).
4. Always fill out comment cards, noting the deficiencies in the "handicap accessible rooms", e.g., room far from door or elevator, shower head in wrong position.
5. Always tell the manager of the motel or restaurant about the inadequacy of placement of grab bars in the bathrooms.
6. Always tell the managers about the inadequacy of handicap parking, e.g., too far from door, not wide enough, not near ramps.
7. Do repeat business at the motels/hotels that do a better job, especially by requesting a specifically numbered room that was satisfactory in a past visit.
8. Note where there is inadequate space for the scooter or wheelchair.
9. Always thank people that help you, including a smile.
10. Although some large businesses provide scooters, be prepared to have your own transportation (especially since most of the provided scooters are not suitable for tall or large people). When you do use the provided scooter, treat as if your own, do not abuse the service.
11. Use a cane of the right height, e.g., adjustable. Use canes that include a "spring" to ease stress on the elbow.
12. Use a "booster" or "up-lift" seat in restaurants, always request a chair with arms (if available).
13. Do not be shy about requesting assistance; most people are glad to help, just be prepared to suggest to them what to do to best accommodate your specific needs.
14. Remember to let your caregiver have some "down" time to recover from all the efforts of taking care of you.
15. Bring your own "long straws" and whatever other special drinking or eating aids you need. Ask for extra napkins, then use at least some of them (e.g., to clean up)