

Tipping Point #2: The first time a mobility aid is needed

Not everyone with MS needs mobility assistance so this tipping point may not apply to you. If it does, however, now is the time to begin gathering information about the range of assistance devices that can help you maintain stability. Just as knowledge is power when you first learn of your diagnosis, so preexisting knowledge about mobility aids will greatly help if your stability needs escalate. You will be more efficient with your resources (time, money and emotional well-being) if you know the range of available tools before you need them. The middle of an exacerbation is not the time to analyze the pros and cons of mobility assistance devices! Being prepared beats being surprised when your personal safety is concerned.

What if you suspect you may need a mobility aid but don't yet have one? When is it time to add a device for occasional use or as part of your daily routine? Consider the following questions: Am I safe? Will I be more stable if I use a device? Do I have enough energy/endurance for the activities I want to do? Will a mobility aid allow me to fully participate in activities with my family and friends? Will it make it easier for my family and friends to do activities with me? Will I be able to move faster and thus keep up with others? If you think the quality of your life will improve with a mobility aid, it is time to add it.

Another way to approach the decision is to analyze the impact of a potential fall. What are the economic and psychological consequences? Will a fall jeopardize my income-earning ability? If I injure myself, will I need caregiving? Can I afford to pay for it? Can a family member take on caregiving responsibilities? If so, will this affect his or her income-earning ability? How will caregiving costs and responsibilities affect my family's budget and interrelationships? In reality, a fall could have a snowballing effect on you, your finances and your family.

If, after doing a personal cost-benefit analysis, you decide it is time to add a mobility device to your life, there are several actions you can take.

1. Start by reviewing articles from previous MSQLP newsletters. They are all available on our website: www.msqjp.org. Go to the Newsletter link.

The **November 2008** issue on Transitions Related to Mobility includes articles about transitions and interviews with persons with MS who have dealt with mobility issues.

The **February 2008** issue on Transitions Related to Housing includes

articles and interviews with persons with MS who describe how adaptive devices allowed them to have better quality of life in their own homes and, more importantly, allowed them to stay in their homes.

2. Update your medical file. Make sure your list of medicines (including herbs or supplements in your regimen) is current. Continue to identify changes in symptoms and concerns you wish to discuss with your doctors. Make sure you identify any changes related to instability. Take this file with you to all medical appointments so that your health care providers have the most up-to-date information.

3. Make an appointment with your primary care provider or your neurologist to discuss the most appropriate mobility aids. Will a cane provide sufficient support or would braces or a walker better meet your needs? Once you know which you want, you must be measured so that the device provides the best support. For example, not any cane will work—it needs to be the right length to match you height.

Visit a medical supply store in your area. They will show you a range of mobility devices that will meet your needs. They will have brochures describing the equipment. Ask for copies and start a file. You can review them at home when you have more time and the ability to better concentrate. Once you have your device, call your doctor, neurologist or physical therapist for assistance in learning how to best use the new mobility aid.

4. Review your insurance policy for its coverage of durable medical equipment. Hopefully, your needs will match its coverage. If so, you will need a prescription for the device from your doctor. If not, you need to investigate other funding sources. Check the online websites of National MS Society, MS Foundation and the American MS Association. If you qualify, you will need the prescription, the invoice, and the denial of coverage notice for the specific device from your insurance company.

5. Ask your primary care provider for a referral for a home visit by an Occupational Therapist (OT). The OT can do a home evaluation for mobility safety. For example, could throw rugs catch your toes and make a fall more likely? Would grab bars by the toilet and in the shower serve you well? Are there ways to change how you use your kitchen so that you have more stability? In addition, an OT can help if you lose functionality for some routine tasks—food preparation, folding clothes, personal hygiene. They can show you different ways to do things and teach you simple exercises to help restore strength.

6. It is not too early to start exploring other adaptations that may make daily routines like food preparation, eating, bathing, doing the laundry, etc.

easier if some activities become more challenging in the future. Just as there are many websites and brochures for companies offering mobility-related devices, there are many offering accessibility modifications for your home or daily routines.

The range of products is vast. In a Google search use keywords like: disability products, accessibility product, dressing aids, assistive products, etc. For more ideas, talk with others who have been in your situation. There is nothing like advice from those who have been there.

7. Walk around your residence and look at it from the perspective of an Occupational Therapist. If you should need a ramp, where would it be best positioned? Would it get you into and out of the house/apartment? Can you get to the garage/car? Could you use your bathroom if you needed mobility aids? What changes might have to be made?

Look at your kitchen area critically. Is there room to move around if you were using mobility aids? Can you reach into all the cabinets? If you live in a rental unit, are there any restrictions about changes you can make to your living space? Find out now. You may be able to get low-interest grants for some home modifications. Qualification requirements vary by funding organizations and it can be a little tricky but you may be able to find some help. Go online and start a search.

8. Review the accessibility of your place of employment, the offices of your health care providers (doctors, dentists, physical therapists, etc), favorite restaurants, cinemas, leisure activities, and friends' homes. You may not ever need this information but preplanning helps eliminate surprises.

9. If your mobility is impaired you may need to evaluate how much longer you will be able to drive safely. If you are using a new mobility device, practice getting in and out of the car until you feel confident. You may need to adjust your seating. Explore modifications to your car such as hand controls that increase your ability to drive safely.

Also, be aware that medications may affect your driving ability. Any time you add a new drug to your regimen, analyze if it affects your driving. Explore alternatives to driving. Each county has a paratransit system—RIDES in Monterey/Salinas, ParaCruz in Santa Cruz and County Express in San Benito.

You will need to sign up with the program in your area. Once enrolled you can call to be picked up and delivered to addresses within the company's service area. Each system has its own set of guidelines and procedures. They are online.

10. Although it may seem premature to explore long-term care, the reality is that some home care funding sources kick in as soon as a person has trouble with daily routines like food preparation and doing laundry. Often such services are income-based so it is important to learn if you qualify for such services. They provide funding for a set number of hours per week of home assistance. These are the kinds of services that allow people to stay in their own homes, a very desirable goal.

11. If you want to keep active as long as possible consider joining the Adaptive P.E. program at your local community college. Go online to the college's catalog and read about the program at your college. Meet with the program director and learn how you can get started on a regular exercise program designed to meet your needs. Find out what is needed to enroll. For example, a doctor's prescription or waiver may be required.

12. Complete an Advance Directives Planning document. This may seem like quite a stretch—asking you to complete a living will—but the reality is that everyone should complete one. We know this because we have heard stories about client's wishes not being followed. We cannot repeat this strongly enough—everyone reading this newsletter, EVERYONE, whether you have MS or not, should complete a living will.

The document we like best is called Five Wishes, developed and produced by a non-profit agency called Aging With Dignity. The document is self-explanatory. You read it, complete it and give a copy to your doctors, family members and the person you identified as your durable power of attorney for medical decision. It lets everyone know whom you want to make health care decisions for you if you can no longer make them. It identifies what kinds of medical treatment you do and do not want.

You make the choices about how you want to be treated. The 5 Wishes meets legal requirements in California and 40 other states. Their website will answer questions you may have. You can order a copy of the document from their website. Once it is completed, review it annually. It is a document that can easily be changed or adjusted. You will feel better when this has been done.

Another important document to augment your Advanced Directives Planning document (Five Wishes) is called POLST. This stands for Physician Orders for Life-Sustaining Treatment. It is a document that also identifies your treatment wishes.

What makes this different from Five Wishes is that it is signed by your primary care doctor and kept in your medical chart. It turns your treatment wishes into actionable medical orders and is portable from one care setting to another.

Again, it doesn't replace the Five Wishes but should be used with it. California has a POLST program in place. Go online <http://www.ohsu.edu/polst/> to download the forms and then take them to your doctor. The two of you will identify what you want and then your doctor will sign it. It is not valid without your doctor's signature.

13. Attend an MS support group. If you have not yet attended an MS support group, consider it now. Group members will have advice and stories to share about their experiences with mobility aids. Use their knowledge to improve your own life. See the end of this newsletter for the list of meeting times and locations of support groups in the Tri-Counties.

14. Continue to share your thoughts, beliefs and experiences with the members of your personal support group—those people with whom you can share what you are going through. If any member wishes to attend a caregiver support group meeting, encourage them. It will give them a change to talk with others who support persons with MS. Share your written and online resources with them; information will empower them as well as you.

15. Agencies that may help explore issues related to this tipping point:

Living Will/End of Life documents:

Five Wishes: www.agingwithdignity.org

POLST: <http://ohsu.edu/polst>

Paratransits:

RIDES (Monterey County): www.mst.org/rides

ParaCruz (Santa Cruz County): www.paracruz.com

County Express (San Benito County):

www.sanbenitocountyexpress.org

Local Community Colleges – Adaptive P.E. Programs

Monterey Peninsula College (Monterey): www.mpc.edu

Cabrillo Community College (Aptos): www.cabrillo.edu

Hartnell Community College (Salinas): www.hartnell.edu

Gavilan Community

The Best Thing I Did When I First Had to Use a Mobility Device

By Carrieanna Hess, Graduate Student, Cal State San Diego Masters Degree Program

When I was 22 years old, in the spring semester of my senior year at Cal State Monterey Bay, I began having trouble with my balance and gait. I would often lurch and stumble as I walked across campus. My friends made comments about how it looked like I was getting drunk in the middle of the day. Although I had already been diagnosed with MS, I had not seen anyone about getting a mobility aid. I knew I didn't want to use a cane—not when you're in college, please—but I knew I needed help. I was so close to graduating. There had to be something I could do to get through the end of the semester. I went and found my tall wooden walking stick, a staff almost as tall as I am. It gave me the stability I needed and it seemed a better fit for a college campus.

I soon got a new nickname—Gandalf—from *Lord of the Rings*. I guess I looked like him striding across campus with my tall staff. That was fine with me as long as it helped me through the last weeks of college. Not long after I graduated I met with a physical therapist who prescribed a single-point cane and taught me how to use it. I switched to the cane and it worked well—but I am grateful for my trusty walking stick. It did the job when help was needed.