

November 2009

MS Quality of Life Project

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Tipping Points

- #1 Diagnosis
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Tipping Points

**By Donna Krasnow,
MSQLP Board Chair**

The intent of this newsletter is not to scare you; we want, instead, to empower you to take as much control as possible over your future. Our case managers at MSQLP have learned over the years that there are key points in the progression of MS, key points that greatly affect the direction of one's future quality of life. We call these "tipping points," a term first identified by Malcolm Gladwell in his book, *The Tipping Point*. He describes these points as dramatic moments that change a group, an organization, or society as a whole. At the time of occurrence one might not perceive the significance of the moment but, in the long run, its impact is profound. In this issue we apply his concept to MS.

We have identified 5 moments in MS—5 tipping points, so to speak—that we believe may trigger significant changes in the life of a person with MS. They are: 1) Diagnosis; 2) When a mobility aid is first used; 3) When MS affects employment; 4) Cognitive changes; and, 5) Inability to transfer. Although we know that each person's path in MS is unique and that rates of progression differ, we know some degree of degeneration will occur and that each of us will experience some or all of these tipping points. We also believe that, although each may be

difficult to accept, each represents an opportunity for proactive management of MS. If we take appropriate actions at the onset of a tipping point, we may reduce its impact on our lives. If we don't, the impact may be profound and result in financial, social and emotional crises that we cannot adequately meet and leave us with an increasing sense of isolation.

We believe that advance planning is the key, and that it is ideally done with the assistance of a social worker or an MS nurse. They have knowledge of the disease and of community resources that address its impact. It may be beneficial to be associated with an MS center where health care professionals work together on addressing the needs of common clients. We realize that this may not be possible for all Tri-County persons with MS, given that the MS Centers at UCSF in San Francisco and at Stanford in Palo Alto may be inaccessible geographically or financially. Whether you attend an MS Center or not, experiencing any of these 5 tipping points should be viewed as an opportunity to take actions to limit its impact on your life. If you have already experienced a tipping point, it is not too late to take the identified actions. The tragedy would be to take no action and allow the tipping point to play out to its most negative extent.

When we initially identified this topic we had no idea it would become as lengthy as it turned out. We can't fit the discussion of all 5 tipping points into this one issue. This issue includes the first 3. The last two will be part of the February or May 2010 issues.

We thank all of the people who spoke with us during our development of this issue. You graciously agreed to let us share your experiences with others.

Tipping Point #1: Diagnosis

By Donna Krasnow, MA, Andrea Dowdall, MSW, MEd, Marion Brandis, MA, RN, MSCN, Amy Lamb Heckel, RDH

Can anyone forget the exact moment when you learned you had MS? You had known there was something wrong but this was the moment when the diagnosis was confirmed. You had a disease that, even if you didn't know much about it, you knew was really serious. The initial uncertainties associated with how your life might be affected by MS must have deeply shaken you. This was, indeed, a tipping point. In such a situation it is much easier to avoid thinking about ramifications, to not allow yourself to picture how your life and plans may change. Why dwell on negativity? Isn't positive thinking supposed to help disease management? Well, yes, it actually is—but sticking one's head in the sand does not constitute positive thinking. Taking the actions listed below may initially scare you because you will learn so much about your disease but we also believe this knowledge will ultimately empower you. We believe that taking these steps may lessen the emotional and financial impact of MS when, and if, changes in abilities occur. You don't have to tackle them all at once. Take a breath and work on them gradually while you adjust to any changes you may be experiencing.

1. Learn as much as you can about MS. Yes, you will learn about symptoms and prognoses that may never be part of your MS, but it is better to be prepared than to be surprised by an unexpected development in

your disease progression. There are great websites containing valuable information that will help you understand your disease. These include the MS Foundation, the National MS Society, MS Association of America and the Rocky Mountain MS Center. Our website has links to all of them. Go to www.msqjp.org and click on MS Info. In addition, our case managers at MSQJP meet with those who are recently diagnosed. We can discuss the disease with you and identify ways in which our organization may help. All of our services are free. Call our office (831) 333-9091 if you would like a consultation.

2. Start a medical file that is updated continuously. It should include:
- A copy of your MS diagnosis written by a physician (it may be written on a script pad). You may need this as support for future claims for financial and social service resources.
 - Copies of MRIs – they are usually given to you on disks.
 - An updated list of medicines you take regularly, including any herbs or supplements in your regimen.
 - Information you wish to share with your doctor—a list of symptoms you exhibit, concerns you have, etc. While not everything you experience as a symptom will be due to the MS, it may take some time for you to discern which ones are MS-related.
 - Private healthcare insurance, Medicare, or MediCal information (ID and group plan numbers, e.g.)

Take this medical file with you to all health care appointments—and don't forget your dentists. Some medicines may cause dry mouth and other problems that your dentist should know about. Bringing your file with you will ensure that your doctors have your most up-to-date information and that you don't forget any issues you wish to discuss with your physicians.

3. Consider beginning a relationship with a comprehensive MS care center (in our area there are two: one at UCSF in San Francisco

and one at Stanford University in Palo Alto). There are advantages in having their clinicians know you and your MS from baseline. Even if you can only go once per year and are followed locally by a general neurologist for prescriptions and exacerbations, the opportunity to learn about MS and be cared for by experts who see hundreds or thousands of patients a year can be a good thing. In addition, in some (not all) parts of our service area, local neurologists will not prescribe the most common MS drugs. You may need to go to the MS centers to become part of these programs. Check with your own neurologist. Finally, many of our local neurologists have used the MS centers for second opinions in the initial diagnosis phase and have worked with them when determining if there is a change in your diagnosis (from one category of MS to another). Having said this, some of our clients have reported challenges when working with the MS centers: records getting lost, trouble getting prescriptions filled, difficulty getting appointments in a timely manner. So keep expectations realistic. There are always advantages and disadvantages when dealing with large institutions and the MS centers are no different. One important note, however, if you decide to use an MS center be sure you sign releases so that information flows between your local neurologist and the MS center.

4. If you and your neurologist have decided to participate in one of the major MS drug programs (Avonex, Betaseron, Copaxone, Rebif or Tysabri), be sure to take advantage of the support systems provided by each of the programs. These include nurses who will speak with you on the phone or come to your house to address specific needs. There are also phone or online support groups for many of these drugs which may be a great resource regarding side effects, use

techniques, etc. The drug companies sponsor some of these support groups, others are independent.

5. If you have private insurance (not Medicare or MediCal), contact your insurance company. Ask if they will assign a case manager to handle all future claims (you'll need to tell them that you've been diagnosed with MS). If they will, this will make your relationship with your insurance company easier because there will be one consistent person with whom you speak regarding benefits and claims. He or she will become familiar with your needs. We need to add a caveat here. If your insurance is provided through your work (especially if you work for a small firm) you may want to consider the ramifications of disclosing your medical status—see Tipping Point #3 about employment.

6. Although you may not need to use all of the services provided by your insurance company, carefully review your insurance plan's coverage in reference to: doctor visits, drug coverage, durable medical equipment (this identifies which, if any, medical equipment your insurance will cover—everything from a cane and a commode to a motorized wheelchair), home care provisions (Will they pay for skilled nursing facilities, assisted living facilities, or visits from such agencies as Visiting Nurse, and if so, how many visits in a year?), rehabilitation services (How many in-patient and out-patient visits in a year?), and mental health services (How many psychotherapy or counseling visits in a year?). This is among the most important information you can have. It identifies your entitlements. Make sure you understand what each section of your policy actually means. If you are unsure, call your insurance company's benefits department for clarification.

7. Attend educational events about Multiple Sclerosis. MSQLP offers one or two per year, as do the National MS Society, MS Foundation, MS Association of America and pharmaceutical

companies. At these events you will learn about the latest MS research, drug programs in the works or those that are newly released, information about treatment of specific symptoms, and more. Most offer Q & A sessions so you can have your own questions answered. One great thing about these meetings is that the tone is usually quite positive. We are getting closer to answers. Our newsletter identifies many of these events.

8. Attend an MS support group. Although this may be difficult if you have recently been diagnosed because you may meet people who have a more advanced stage of MS than you, remember, this is the one group of people who completely understand what you are going through. They have been there before you. They have experienced what you have experienced. They are there to provide emotional support to each other. No one else will quite understand the way that they will. There are MS support groups throughout the Tri-Counties. MSQLP sponsors four: two in Seaside (one for persons with MS and one for caregivers), one in Santa Cruz and one in Salinas. National MS Society sponsors one in Monterey and one in Santa Cruz, and one in Hollister. Meeting times of all these groups are listed near the end of each newsletter.

9. Learn about MSQLP's Supportive Therapy program. This program's group sessions (one session per week for 8 weeks) offers participants a chance to work on the feelings they have, the challenges they face and how their MS affects their relationships. Call the office to learn more about our program and to discuss whether it might be appropriate for you.

10. Identify the members of your personal support group. Who among your friends, family and acquaintances try to understand what you are going through? Who is supportive in a positive way? Who listens while also challenging you to be the best you can be? Who helps you make choices that may not support what others want but are best for you in the long run? With whom do

you feel comfortable? Who will join you in a frivolous moment when frivolity is needed? These are the members of your personal support group. It may be small or large—either way, recognize and cherish them. They will be your rock as, hopefully, you are to them. Talk with them about your MS and its challenges. Share what you think, know and believe. Listen as well. If any member wishes to attend a caregiver support group meeting, encourage them. It will give them a chance 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.

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

Information about MS:

- MS Association of America: www.msassociation.org
- MS Foundation: www.msfocus.org
- National MS Society: www.nationalsociety.org
- Rocky Mountain MS Center: www.mscenter.org

Local MS Care Centers

- University of California at San Francisco (UCSF) MS Center: www.ucsf.edu/msc
- Stanford University MS Center: <http://neurology.stanford.edu/divisions/ms.html>

Support Services for Major MS Drug Programs

- Avonex Services: www.avonex.com
- Beta Plus (Betaseron): www.betaseron.com/patients/betaplus
- Shared Solutions (Copaxone): www.copaxone.com/supportservices/default.aspx
- MS LifeLines (Rebif): www.ms lifelines.com/global/about-ms-lifelines.jsp
- Touch Prescribing Program (Tysabri): www.tysabri.com

The Best Thing I Did When I was First Diagnosed with MS . . .

*Marilyn Howell, MSQLP board member,
Marriage and Family Therapist*

The best thing I did when I was first diagnosed with MS was listening to my husband. To me, hearing the words that I had MS set off a bomb inside me. I envisioned the absolute worst scenario—I would soon be in a wheelchair, I could not work, I couldn't live the life I had at the time of diagnosis. Basically, I believed my life was over. But, gradually, my husband's words began to make it through the negative curtain I had drawn over my future. He looked up statistics about MS and started feeding them to me. Two-thirds of people with MS remain able to walk, although many will use assistance. New drug programs are making great strides in slowing the rate of degeneration. Most people with MS have a normal or near-normal life expectancy.

Over the next months I began to understand that my life, although changed, was not over. For example, I did not realize that I was in a flare-up as I was walking around, running into walls, while the room spun around me from my vertigo. My doctor hadn't told me. What I needed was other people with MS to talk with and there was no support group where I lived at the time. That's why I am so passionate about MSQLP. I needed their services in 1998 but they didn't yet exist. I had to go hunting for help on my own. I found a psychiatrist who had MS. I went to see her to find out how I could continue my work as a therapist when I had MS. She helped me in many ways but mainly she helped me grieve about my diagnosis. You need to grieve so you can move on. And she was the one who told me I was in a flare-up.

It's funny, I now look back on—MS can certainly throw the unexpected at you. I had to emotionally recognize that I am a person with MS but that is not the only way to define me. I am much more than my disease. My advice? Figure out how you can do what you want to do—and then do it.

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.msqlip.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 College (Gilroy):

www.gavilan.edu

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.

Tipping Point #3 - When MS Begins to Impact Employment

Many of us identify who we are by the job we do. It's often how we describe ourselves to others. "I'm a teacher." "I'm in construction." "I'm an office manager." But what if MS begins to affect how well you are able to do your work? Is the print on contracts becoming too difficult to read? Am I so tired by 2 p.m. that I worry about making it through the rest of the day? Am I having a harder time remembering or retrieving pertinent information related to my responsibilities? MS may, indeed, affect productivity at work and that, of course, triggers other questions. What will happen if I can no longer work? How will I survive economically? How will it affect my health insurance and other benefits? How will it affect my family? If we believe that MS may affect productivity at work, we also believe that accommodations may effectively address some diminished abilities. But that brings up another issue. If I disclose my MS to my employer to justify my requested accommodations, might I jeopardize retention of my job? Could I be fired because I have MS? We know it's illegal to do so but we also know it may not be easy to prove and, in reality, illegal things happen. So, once again, we need to be proactive to lessen the impact of this tipping point on our lives.

1. Start by reviewing an article from a previous MSQLP newsletter, **November 2007**. It is available on our website: www.msglp.org. Go to the Newsletter link. It has an article on *Employment and MS* that starts on page 6. The article summarized what had been discussed at an MSQLP educational event on MS and Employment that had been sponsored by EMD Serono. It includes information about work and fatigue, to disclose or not to disclose and workplace accommodations that may work for you,
2. A major decision is when (if ever) to disclose information about your MS to your employer. There is no rule that applies across the board. Even though it is illegal to discriminate against persons with disabilities, we have clients who believe they lost their

jobs once employers became aware of their disease. It may not have resulted in immediate dismissal (that would make discrimination much easier to prove) but they believe their disclosure played a role in their eventual dismissal. Other clients have reported very successful adaptations made in their work environment that supported them as they pursued their careers. You need to carefully consider whether or not to disclose, and if so, to whom? The National Multiple Sclerosis Society's website has an excellent overview of the issue of disclosure. It includes sections on *Should I Tell? Whom Should I Tell?* and *How Much Should I Tell?* It also has a downloadable worksheet you can use to help you analyze the pros and cons of your own situation. It does not prescribe an answer—you are the one who has to make that decision—but it gives you the information you need to find the answer that is best for you. Go to www.nationalmssociety.org and click on *Living with MS* at the top of the screen. Scroll down and click on *Employment* (on the left). You can then click on *Disclaimer Decisions, Knowing Your Rights, and Workplace Options*. The more information you have, the stronger your position will be at your place of work. Each of these sections of the website has important information you should know. Read about the Americans With Disabilities Act so you know your rights.

3. There are adaptations that may help you maintain your productivity. The Office of Disability Employment Policy sponsors the Job Accommodation Network (JAN) that has much helpful information on accommodations and compliance. One paper focuses on accommodations that may be useful for workers with MS. (Go to www.jan.wvu.edu. Click on *Accommodation Search* at the top of the home page. On the next screen, click on the large question mark. Then scroll down and click on *Multiple Sclerosis*). It identifies possible accommodations that address the following issues: Activities of Daily Living, Cognitive Impairment, Fatigue, Fine Motor Impairment, Gross Motor Impairment, Heat Sensitivity, Speech Impairment, and Vision Impairment. Many would be easy to implement and would make your workstation,

schedule, parking situations or transportation system better adapted for your needs.

4. Just as an Occupational Therapist (OT) can help persons with MS assess the safety of their home environment and recommend appropriate adaptations, the same OT can help you identify possible accommodations that would better meet your needs at your place of work. Ask your primary care provider for an OT referral.

5. If you believe you will not be able to continue the work that you presently do because of developments with your MS, it may be time to explore other types of work. Review your resume. What skills do you have that may be transferable to other jobs? Focus on your strengths, not your disabilities. You may want to consult with a vocational rehabilitation counselor at a local community college or university. They are trained to help people move into job placements in which they can be independent. They have knowledge of college programs that can help you transition to different types of employment. Also, let your network of professional colleagues know you are exploring other options. They may have ideas.

6. How will you economically survive when you stop working? If you work until retirement, have social security and a pension or IRAs put aside, you may have few concerns. But if you have to leave work earlier than expected because of your MS, you may not have as many options. It is important to make plans now so that you are prepared if employment conditions change for you.

- Do you have disability insurance? If so, read your policy carefully. Call your insurance company to discuss any sections you do not understand.

- Investigate whether you qualify for Social Security Disability Insurance (SSDI), a national program, or State Supplemental Income (SSI/MediCal), a state-funded health insurance for which you may be eligible based on financial need. It may take years to actually qualify (as there are strict guidelines about past

earnings and assets) but, if you understand the requirements, you will know when you are eligible to enroll.

- Work with a financial planner—he or she may have ideas for using your income in more productive ways and how you can best plan for an uncertain future. Obviously, the sooner you make plans, the better it will be for you.

7. 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 employment. 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.

8. 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.

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

National MS Society:

www.nationalmssociety.org

The Office of Disability Employment Policy:

www.dol.gov/odep Job Accommodation

Network: www.jan.wvu.edu/

Social Security Disability Insurance (SSDI):

www.ssa.gov/disability

State Supplemental Income (SSI/MediCal):

www.ssa.gov/ssi/

California Department of Rehabilitation:

www.dor.ca.gov

The Best Thing I Did When MS Affected my Employment ...

By Amy Lamb Heckel, RDH

My paramount symptom is heat intolerance. The operatories (treatment rooms) in the dental office where I work all have large, unshaded skylights. As an accommodation I now work in the mornings only, thereby avoiding the afternoon sun streaming directly onto me. This required that my boss give up one of his operatories on Monday mornings so that I could use it instead—which he did. Preventing contamination by blood borne pathogens dictates that I wear long sleeves, gloves, and a mask. To keep cool I place a dampened paper towel inside my mock turtleneck, open the window, and have a fan that I can direct at myself without it blowing on my patients. This works—and so do I!

By Tracy Tucker, MSQLP support group leader and technology advisor

The best thing I did was disclose to an HR Occupational Nurse where I worked that MS was affecting my productivity. This was 8 years after I was diagnosed with MS. I was then working as a technical professional in a field where learning speed and information recall were key to job performance. Many years earlier, I had asked my manager if I could move to a cooler office because my office was very warm in the afternoon which triggered my MS heat sensitivity and affected my ability to work. My manager had arranged this office move, but in later conversation with subsequent managers, I was surprised to learn that my disclosure had not become part of my permanent employee record, probably due to corporate privacy guidelines. When I later began to experience cognitive problems that affected my productivity, I decided to investigate a career that might be a better fit for me given my MS. I found a program in Boston that taught piano technology. I had studied piano performance for many years, and I liked the idea of tuning and maintaining pianos for performing artists. I discussed my

plans with my manager at the time, along with my reasons for these plans. She was very supportive and arranged an unpaid one-year sabbatical for me for this training. She also arranged that I contact an Occupational Health Nurse in Human Resources to discuss my health issues. At the request of this nurse, my doctor sent in a Medical Treatment Report that documented my medical condition and its impact on my career. This report became part of my permanent employee record in HR.

As much as I enjoyed the program in Boston and the summer I worked at Tanglewood, I soon recognized that lower body weakness and poor stamina would make such work unsustainable for me. I returned to my life as a software engineer with my original employer. I continued to work another 10 years, but I knew that my productivity was continuing to decline. My yearly performance evaluation indicated this. Although I asked for accommodation under the ADA (work at home, for example) this was not granted. Eventually I was given a 3-month notice to look for work elsewhere. I, once again, contacted the HR Occupational nurse that I had been in contact with off and on since my return. My doctor sent in another Medical Treatment Report and I quickly qualified for short-term and eventual long-term disability. So for me, the decision to disclose my MS changed my life positively in terms of financial security after I was no longer able to work as a software engineer.

So what has helped me now that I am no longer working? First, I have found ways to stay busy and socially connected by volunteering my time to help others. Second, I strive to set realistic goals for myself every day. Too often I plan to complete too many things in one day, and then end up feeling frustrated by my lack of success. I need to remind myself to set realistic goals and to more fully enjoy fewer activities.

By Tammy Jennings, MSQLP Volunteer

The best thing I did was quit. I started using a wheelchair 11 years into my job. It certainly helped with mobility but it did not solve all my problems. I used the chair for 2 additional years

but, looking back, I realize I was struggling much of the time with hand tremors, memory/cognition problems, and urinary/bowl incontinence. Fatigue was still my biggest obstacle, however. The wheelchair saved some energy but not enough. I was still so fatigued after working eight hours that all I could manage was to go home and sleep. It was hard to get through each day. By noon 90% of my energy had already been depleted.

I also hadn't realized how my attitude had changed. I was angry and frustrated most of the time and apparently wasn't very good at hiding my emotions, as my co-workers pointed out after my departure. They said that the "old Tammy" reemerged once I quit working.

I'd been afraid to quit because, with the loss of my one and only source of income, what would I do? How would I survive without being a burden on anyone? (I pride myself on being independent and self-sufficient.) Well, before I quit, I tried to get all my ducks in a row. I called the Social Security Administration and found out what my Social Security Disability Income would be after my State Disability Insurance ran out. Also, would I be eligible for Medicare when my employer-provided health insurance ran out as I was only 47-years-old at that time? Additionally, I inquired about other assistance available to me, i.e. Monterey-Salinas Transit RIDES, Meals on Wheels, etc. After 2 years of my doctors telling me I should "retire," I did. Today, I live frugally but I am surviving. On the plus side, I have much more energy because I am able to sleep/rest when I feel the need. I have also been able to travel, volunteer, and take some classes to enrich my mind. Additionally, my attitude and outlook on life in general is very good. Basically, I live my days as I want to live them . . . I am finally taking care of ME. So, retiring from my job was actually the best thing I could have done.

MS Support Groups

Anyone dealing with MS on their life journey is welcome to attend, whether as one with MS, a family member, caregiver or friend.

MSQLP sponsored groups:

Oldemeyer Center: 986 Hilby Ave. Seaside
Second Saturday of each month
11:00 am to 1:00 pm

MS Caregiver Support Group

Seaside Second Saturday of each month (Also at Oldemeyer Center, meets in separate room from MSer's support group)
from 11 am to 1 pm

Lorna Wheatley Memorial Support Group at Salinas Valley Memorial Hospital

Downing Resource Center
Third Friday of each Month, 11:00 am to 1:00

Santa Cruz Skilled Nursing Center

2990 Soquel Avenue, Santa Cruz
Second Thursday of each month
1:30 pm to 3:00 pm

Times and locations are subject to change, please call the MSQLP Office at 333-9091 for current information.

National MS Society sponsored groups:

Monterey

Community Hospital (CHOMP)
Last Wednesday of each month
7:00 to 8:30 pm
Call Susan Jones at 659-1354

Santa Cruz

United Way, 1220 41st Ave. Capitola
3rd Saturday of each month
10:30 am to 12:30 pm
Call Ada Shannon at 440-1211

San Benito

New Fire Hall, Airline Highway, corner of Union, Hollister
Last Friday of each month
6:30-8:30 pm
Call Gina Lucas at 636-3241

Calendar

November

- 25 Water Aerobics, Monterey
- 25 Support Group NMSS, CHOMP
- *San Benito Support Group- Call for date

December

- 2 Water Aerobics, Monterey
- 9 Water Aerobics, Monterey
- 10 Support Group, SC Skilled Nursing Center
- 11 Support Group, SVMH, Salinas, *Downing Room C*
- 12 Support Group, Oldemeyer Center
- 12 Caregiver Support Group , Oldemeyer Center, Bayonet Room
- 16 Water Aerobics, Monterey
- 19 Support Group, NMSS, SCruz
- 23 Water Aerobics, Monterey
- 30 Water Aerobics, Monterey
- 30 Support Group NMSS, CHOMP
- *San Benito Support Group- Call for date

January

- 6 Water Aerobics, Monterey
- 9 Support Group, Oldemeyer Center
- 9 Caregiver Support Group , Oldemeyer Center
- 13 Water Aerobics, Monterey
- 14 Support Group, SC Skilled Nursing Center
- 15 Support Group, SVMH, Salinas, DRC
- 16 Support Group, NMSS, SCruz
- 20 Water Aerobics, Monterey
- 23 Water Aerobics, Monterey
- 27 Water Aerobics, Monterey
- 27 Support Group NMSS, CHOMP
- 29 San Benito Support Group

Development

We want to thank our dedicated donors. People who help MSers are our heroes! Since our last newsletter we have received donations from:

Richard and Lynda	Cornell
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Norman and Fran	Leve
Charlotte	Muia
	Multiple Sclerosis Foundation
Kent	Newbold
Lynne Seme	Ria
Clive and Sally Anne	Smith
Katherine and Floyd	Wenglikowski
Mary	Wessling, PhD

Please Join us to Celebrate with our Friends at

MSQLP'S SUPPORT GROUP HOLIDAY PARTIES

Thursday, December 10, Santa Cruz Skilled Nursing Center
2990 Soquel Avenue, Santa Cruz
1:30 pm to 3:00 pm

Friday, December 11, Lorna Wheatley Memorial Support Group at Salinas Valley Memorial Hospital
Downing Resource Center , Room C,
11-1pm

Saturday , December 12, Oldemeyer Center and Caregiver Support Groups, 11-1pm

**MS QUALITY OF LIFE PROJECT
519B HARTNELL STREET
MONTEREY, CA 93940**



***Return Service
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We're on the Web!

See us at:
www.msqlp.org

After Words

Because of the length of this newsletter we have not included Tipping Points #4 (Cognitive Changes) and #5 (Inability to Transfer). These will be added to our website in December and will be printed in our February or May newsletter. If you do not have access to a computer and do not want to wait for the next newsletter, call the office and we will send you a printed copy of the last two tipping points. In addition, due to the length of this issue, we have eliminated the usual MSQLP news items. They will return in February.