

MULTIPLE SCLEROSIS SOCIETY OF PORTLAND, OREGON INC.

MULTA SPES

MUCH HOPE

IMPROVING THE QUALITY OF LIFE FOR THOSE WITH MS SINCE 1949

Director's Notes: by Candyce Hayes

Fall 2011 Issue



Summer finally hit Portland and not a minute too soon. As I write this article, it is 90 degrees outside and clients are calling for air conditioners, cooling vests and fans. I'm delighted we were able to gift 26 air conditioners and 3 fans this season thanks to sponsors. By the way, we don't carry cooling vests. Summer Comfort is my favorite MSSP program service. It's like playing Santa in the middle of summer!

Meanwhile the massage program was revived. Acupuncture has been so well received we're thinking of adding a Saturday evening session. Clients

consistently say how much acupuncture is helping relieve a host of MS symptoms. Let's see what else have we done lately? Oh yes, we cleaned out the medical equipment closet. It's now nice and tidy. I suppose it's time to focus on cleaning up my desk. It's amazing how things pile up. Ah, housekeeping you just can't avoid it.

This leads me to change subjects and focus on something very serious: advanced directives and final testaments/wills. They are one of those "life housekeeping chores" everyone needs to do. We've got a great article on advanced directives in this issue (refer to page 3 for full details). Now I'm going to share my personal story in the hope it will benefit our readers.

My mother died on a crisp October morning in 1982. She was only 46 years old. She died intestate. That means without a will. Her death was completely unexpected. What followed was a nightmare. First we were in shock. My sister and I, barely in our 20's, were unprepared to handle such matters. Reeling from grief we made the best

choices we could and then crossed our fingers we'd done right by her.

Next were the financial shocks. Everything was so expensive. I guess the first and last thing you do on this earth is incur a bill. It seemed like attorney fees and taxes took way too much of her estate – all consequences of not having a will. What I learned was *you're never too young to prepare your estate. Next make sure family members know where your will is and what you want.* Indeed one of the best gifts you can give your loved ones is to make your final wishes known. I hope my story helps you take action. It's a story needlessly repeated every day.

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Multa Spes is the quarterly newsletter of the MSSP, distributed to MSers, consumers, families, professionals and friends.

Comments and articles are welcome. Publication depends on space available and is subject to editing. The next submission deadline is: 12/01/2011.

Please send submissions to Candyce Hayes, Executive Director, at: candcycehayes@msoregon.org or mail: MSSP, 2901 SE 122nd Ave. Portland, OR 97236.

If you are not currently receiving Multa Spes by mail, we would be happy to add you to our mailing list. Direct all subscription requests or address changes to candcycehayes@msoregon.org or call 503.297.9544.

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FYI:

SE Portland Community Qigong
Is on Monday, Tuesday & Thursday mornings in the inner SE Portland area.

Qigong means “energy work” and is derived from shamanistic and martial arts. It is a moving meditation designed to expand the breath, tone the organs, raise energy levels and develop a strong sense of Self in Nature.

Interested? Cost is between \$5-10 on a sliding scale. Contact Marian Wolfe Dixon at 503.232.7282 for more information and registration.

MS Research Trials

The Summit Research Network Management, Inc., located in Portland, has on-going MS research trials. If you are interested give them a call at 503.246.4817.

The OHSU MS Research Center also has on-going MS trials. If you are interested in participating in a research trial, please call the OHSU MS Research line at 503.494.7241.

Adaptive & Inclusive Recreation

has many upcoming events in the Portland metro area. These include day-trips to the Oregon Zoo, the beach, a pumpkin patch and more! Fitness activities and other classes are also available. Visit www.PortlandParks.org or call 503.823.PLAY for more information.



Acupuncture Update

Thank you to those who are participating in our Acupuncture Program. We have heard great success stories of how acupuncture has helped relieve some symptoms.

We are pleased to announce that the program will continue this fall. Currently we offer drop-in group acupuncture on Monday's from 10am-1pm. (Please arrive no later than 12 noon for your hour session.)

Saturday evening sessions are starting soon. If you are interested in Monday morning or Saturday evening sessions please call the office at 503.297.9544. Each session costs \$8-18 based on a sliding scale.

Advanced Directives

**Written by: Laurel Johnson,
LMSW, MSMOL,
Consultant
Oregon Health Decisions**

Everybody knows somebody who has been gravely ill, lived in a care facility, or who has died. These experiences cause us to think about what we would want, or not want, if we were in similar situations. An Advance Directive (AD) is the tool to communicate wishes about quality of living.

Oregon's KEY Conversations – AD Planning Guide is designed to help you and your loved ones understand advance care planning. The guide begins with Conversation Starter stories of real-life “what if” medical conditions, which require decisions about treatment and care options. The discussion questions and definitions help guide your conversation to put ideas, support systems, and a plan in place for your future.

The Individual Worksheet section is the cherry on top of the sundae, the color and music of your life. This is where you write what quality of life is for you. What makes you wake up and greet each day? What makes you happy and content? What makes your life meaningful? Pulling from

your experiences and values, if you were in a tough health situation, like others you have known, how would your values lead your decisions about the life you want? Advance Directives only come in to play when you are at that fork in the road where you would make decisions about quality of life or quality of death. I don't think anybody will be surprised to know that all of us will die at some time. As death is part of life, we do not have to be so afraid when we talk about it and plan for quality.

After completing the middle section about your quality of life, you can complete your legal AD form in the final section. The conversations you had with your family, and your answers in the Individual Worksheet will guide your choices about life support and who you want to make decisions on your behalf if you are unable to speak. On your AD choices, numbers 1-4 on pages 4-5, hand write “See my Individual Worksheet”. The two sections belong together to insure your doctors and decision-makers understand what you want and why.

We are not afraid when we responsibly purchase homeowners insurance. We do not recoil in fear when we buy auto insurance. We do not tremble and live each day in worry when we purchase life

insurance or make financial investments to care for loved ones after we've gone. And we don't wait until we are old and sick to buy these policies. A quality of life AD is an insurance policy, an investment for yourself and your loved ones. The best part is that an AD is FREE. You don't need to pay a lawyer, and you don't have to pay monthly premiums. When that critical time comes, you can have confidence that your doctors and your loved ones will respect and honor your wishes. It is your gift of peace of mind.

Advance Directives are available at your Primary Care Physician's office or at a hospital. You want to get the new KEY Conversations – AD Planning Guide. Forms and information videos are also available through Oregon Health Decisions at 503.692.0894 or toll free 1.800.422.4805. www.oregonhealthdecisions.org

Upon completion of your Advance Directives, give copies to all your doctors and family members so they can easily find where you have recorded your wishes.

Job Accommodation Network: Accommodation Letters

HELPING PATIENTS WRITE EFFECTIVE ACCOMMODATION REQUEST LETTERS

Under the Americans with Disabilities Act (ADA), covered employers must provide reasonable accommodations for employees with disabilities. However, before an employer has any obligation to provide an accommodation, an employee must make an accommodation request and if asked, provide appropriate documentation. Medical professionals can play a key role in the success of workplace accommodations for their patients with disabilities by helping them write effective accommodation request letters and providing sufficient medical documentation. The following discusses what information might be included in an accommodation request letter and related medical documentation.

Using Letterhead

Employers tend to place more value on medical documentation that is on professional letterhead and in some cases, employers

will not even accept medical documentation unless it is on letterhead. To save time and help insure that medical documentation is sufficient, accommodation request letters should be done on letterhead.

Documenting Disability

Under the ADA, when an employee requests an accommodation and the disability is not known or obvious, employers can require medical documentation that the disability exists. The ADA contains a specific definition of disability: an impairment that substantially limits one or more major life activities. Therefore, when documenting that a patient has a disability, medical professionals may want to use the ADA's specific language so the information will be helpful for employers.

The first piece of information to include is the patient's diagnosed impairment. If the patient is hesitant to provide the diagnosis, a more general statement about the medical condition may suffice, but if the employer insists on having the diagnosis it should be provided or the documentation may be considered insufficient. According to the Equal Employment Opportunity Commission (EEOC), documentation is insufficient if it does not specify the existence of an ADA disability and explain the need for reasonable accommodation.

The next piece of information to include when documenting

disability under the ADA is information about what major life activity the impairment substantially limits. There are two categories of major life activities. The first includes, but is not limited to, caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working.

The second category of major life activities is major bodily functions, which includes but is not limited to, functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions.

Once a disability is established, employers have an obligation to accommodate any limitations resulting from the disability, even limitations that are not substantial. One important thing to remember is that the major life activity that establishes that a patient has a disability is not necessarily the same major life activity that is affecting the patient at work and for which the accommodation is needed.

Providing Accommodation Information Under the ADA,

Continued on Page 5

Job Accommodation Network: Accommodation Letters *continued*

employers are responsible for coming up with and providing effective accommodations. However, employers do not always know what accommodations might work so it may be helpful to provide any accommodation ideas that the medical professional and patient have. In addition to accommodation ideas, this part of the letter should include information about what limitations are causing the patient's work-related problems and what those problems are. The goal here is to help the employer understand the problem and start exploring solutions. Here are a few examples:

Example A: Because of Patient X's depression and associated concentration problems, she is having difficulty completing reports on time. One accommodation that might be helpful is to reduce distractions in her workspace. This could be done by moving her to a private office or providing a headset with white noise.

Example B: Because of Patient X's rotator cuff injury and his associated limitations of lifting no more than 25 pounds, pushing/pulling no more than 50 pounds, and no overhead work, he is having difficulty moving some of the boxes in the

warehouse. Accommodations that might be helpful include a height-adjustable lifting device, a small lightweight ladder, and help moving some of the heavier boxes.

Example C: Because of Patient X's progressive vision loss and associated blurred vision, she is having difficulty reading her computer screen and paper copies of reports. One accommodation that might be useful for her computer access is screen reading software. For reading paper copies, a stand magnifier that magnifies four times the regular print may work for now, but because the vision loss is progressive, a better option might be to scan in documents so Patient X can read reports on her computer.

Offering to Follow Up

In the final section of an accommodation request letter, medical professionals should offer to address any specific questions the employer has about the employee's accommodation needs and to discuss other accommodation options if needed. When making an accommodation request, employees want to be careful not to lock themselves into only one accommodation solution because if the employer cannot provide that accommodation, the employer may conclude that an employee is no longer qualified. This final part of the letter helps address this issue by leaving open the door for additional discussion.

Accommodation Request Letter- SAMPLE-on letterhead

Dear Employer Name

I am treating Patient Name for diagnosed impairment, which causes substantial limitations in the major life activity(s) of major life activity or activities impacted by the diagnosed impairment.

Because of Patient Name's diagnosed impairment and associated limitation, he/she has difficulty work-related problem and needs an accommodation. Patient Name and I discussed the situation and came up with the following accommodation ideas:

List accommodation ideas here, and briefly explain how each will address the work-related problem.

If these accommodations cannot be provided, please let Patient Name know so we can discuss alternatives.

Sincerely,
Medical Professional's
Signature

Medical Professional's
Name

KEEPING OUR DOORS OPEN:

The Neu Brothers and MSSP Invite You To The
1st Annual Portland “MJN Help Defeat MS” Slingball Tourney & Mini Marilyn Kids Tourney



Where: North entrance is off SE 7th Ave between SE Lambert St & SE Malden St

When: Sunday, Sept 18th

Hours: 1pm – 6pm (might end earlier)

Adult Entry: \$25 per person
 (doubles tourney \$50 per pair)
 Double elimination tourney

Kids entry: \$15 (single play)
 Double elimination tourney



Pack your pic-a-nic basket and come out to Portland Slingball!

6 ways to support Slingball!

- | | |
|------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none"> • Enter to play • Cheer as a spectator • Purchase \$1 raffle tickets | <ul style="list-style-type: none"> • Silent auction • Purchase “Official” Slingball merchandise • Bring a friend |
|------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------|

Come watch the fun. By the way, if you have MS we'll waive the \$25 participation fee. The MSSP and the Neu Brothers love MSers! All children can play for only \$15. We'll also have a silent auction too. You can even play on the “practice court” if you are shy.

Visit www.msoregon.org/slingball.html for more information and details. Registration forms are available online as well.

Slingball
 .com



From the 5th annual Marilyn J. Neu “MJN Help Defeat MS Slingball Tournament @ Pacific City

Slingball
 .com

Mark These Dates

Event/Activity	Description	Date	RSVP
Acupuncture	Monday drop-ins at MSSP	On-going	Please call the MSSP office for more details
Flu Shots - various locations around Portland Metro Area	See website for public clinics	9/15/11 - 10/31/11	See website details and locations
Christmas Party Montavilla United Methodist Church	Special Musical Guests: Robbie Laws & Friends	12/10/11	RSVP required by 12/2/11
Caregiver classes are available at the MSSP house on an as-requested basis.		Please contact the MSSP if interested.	
Slingball Sellwood Park, Portland, OR	If you would like to play, please register ASAP. To watch please join us starting at 1 pm on September 18th		



PICNIC RECAP: Thank you to everyone, including our volunteers, who came to our Annual Oaks Park Picnic on June 18th. Even though the weather was a little cold and drizzly, over 100 MS'ers and their family members attended. We had a great time socializing and hearing from Allison, who now leads our acupuncture program, and the Slingball organizers Randy, Carter, Tracy & Wendy Neu. As I walked around Oaks Park afterwards, it was great to see many of you enjoying the rides.

PLEASE JOIN US AT OUR CHRISTMAS PARTY

Date:	December 10th
Location:	Montavilla United Methodist Church 232 SE 80th St., Portland, OR 97215
Time:	11:30 - 3:00 pm
Cost:	FREE "Donations Appreciated"
Limit each party:	4
RSVP Deadline:	December 2nd
Call or Email:	503.297.9544 events@msoregon.org or register online at www.msoregon.org/calendar.html



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Yes, I want to help improve the quality of life for persons with MS!

Here is my contribution to the Multiple Sclerosis Society of Portland, Oregon, Inc.

☐ \$250 ☐ \$100 ☐ \$50 ☐ \$20 ☐ other