Multiple Sclerosis Society of Portland, Oregon, Inc.

MULTA SPES

MUCH HOPE

Improving the Quality of Life for Those with MS since 1949

Volume XVII Issue I Winter 2015-2016

Riding the Storm

How MS Affects Your Emotional Control

By Laurie Long

Have you ever found yourself reacting to a situation with an emotional response that was completely out of proportion to the event? Crying over a TV commercial, for instance, or being enveloped in a blinding rage because someone cut you off on the highway? Have you been embarrassed or frustrated by your increasing lack of emotional control? If that is the case, this emotional roller coaster could be a direct result of your MS.

An inability to control the outward expression of emotion is common in MS. The left frontal lobe of the brain is the "neural thermostat." It keeps raw emotion in check. If MS lesions have damaged the frontal lobe's functions, then its ability to regulate mood is compromised. This inability to regulate mood is experienced as intense physical sensations over which there is no control. Many describe it as emotional flooding or storms. Most people coping with MS find that their feelings are closer to the surface than they were before MS became part of their life. Some experience a quick temper and others cry very easily. Their ability to control the expression of strong emotions diminishes due to the physical changes in their brain.

A Toronto study found that 72% of outpatients in an MS Clinic had difficulty regulating their emotions. For some, this symptom appeared years before other more visible motor symptoms started. In fact, one of the initial symptoms of MS may be changes in mood and emotional expression. This is different than the feelings you have in response to the trauma of a diagnosis of a chronic illness. Since people cope most effectively with a chronic illness when they understand the range and severity of their symptoms, it is important to talk openly about emotional symptoms.

Depression

Studies have shown that anywhere from 40 to 60 percent of people with MS suffer from depression. This depression may be caused by their circumstances, can be a physically based symptom of MS, or a combination of both. In fact, studies have suggested that clinical depression, the severest form of depression, is more frequent among people with MS than it is in the general population and even more common than among persons with other chronic, disabling conditions. Depression does not indicate weak character and it should not be considered something shameful that needs to be hidden. Depression is not something that a person can control or prevent by willpower or determination. Discussing it with your doctor and seeking counseling are the first two steps in combating depression.

Depression is a widely undertreated symptom of MS. Individuals experiencing this symptom may become withdrawn from their family or friends and give up interests that previously had meaning for them. They may become shy or inhibited. They are unable to maintain a positive mood – the negative emotional state lasts long beyond the event which initiated it.

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Inside This Issue

Inserts Included

Director’s Notes by Candyce Hayes

I hope everyone is doing well. I’m glad to be in Oregon especially this winter. The east coast has been hit hard with snow. I’ll take rain any day.

Please read this issue carefully. There are many important updates, changes and new programs that we’re excited to announce.

Changes - There are no application deadlines for the air conditioner (Summer Comfort), massage (Project Helping Hands) and Acupuncture programs. Please visit our website at **www.msoregon.org** to apply and get full details.

Effective June 1, 2016 we will no longer mail the “Multa Spes” newsletter instead it will be available online. To continue receiving the newsletter please give us your email address as soon as possible. You can email it to me at **candycehayes@msoregon.org**, call us at 503.297.9544 or complete the insert and return it to us using the envelope provided. If you don’t have access to a computer let us know.

New Programs – Art classes - Channah has graciously offered to teach the first series of free weekly art classes starting March 7th - April 11th 2016 from 1:00 PM to 3:00 PM. The topic will be drawing. Classes will be held in the MSSP annex at 2901 SE 122 Ave., Portland, Oregon. Registration is required. Call Cathy at 503.297.9544 or email me at **candycehayes@msoregon.org** to register. We plan on offering a variety of art classes depending upon the interest. Let us know what types of art you want to learn.

Night at the Movies – beginning March 1, 2016 MSSP will give one gift card per year to any MS client good for one movie at all Portland area Regal theatres. Some theatres offer a free caregiver companion program. Call the theatre prior to confirm they participate in the caregiver program.

Donate – Unfortunately our main fundraising program was 20% lower than budgeted. We ask that you make a donation today to help keep our unique programs and services available. Remember 100% of your donation will be used to support the client program of your choice. You can donate via our website at **www.msoregon.org** or mail it to us using the enclosed envelope. ***Every dollar counts so please donate now***.

Lastly please join me in welcoming Phyllis VanderVeer to our Board of Directors and Cathy Woodcock who has joined the office staff. Libby left to pursue a job closer to her woman’s studies degree.

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. Submission deadlines are: 3/15/2016 and 5/15/2016.

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

If you are not currently receiving Multa Spes, we would be happy to add you to our mailing list. Let us know if you want it by snail or email. Direct all subscription requests or address changes to candycehayes@msoregon.org or call 503.297.9544.

Riding the Storm

How MS Affects Your Emotional Control

By Laurie Long

They can't bounce back from a stressful life event like they could before the MS. They can become stuck in a stressful, unregulated, disorganized state of raw emotion. Feelings of shame, humiliation and loss can overwhelm the person. Fortunately, depression often responds well to treatment. Tricyclics (Elavil, Tofranil, Pamelor), selective serotonin reuptake inhibitors (SSRIs) (Prozac, Zoloft, Paxil, Celexa), and some of the more recent antidepressants (Effexor, Serzone, Wellbutrin, Abilify) are all available with your doctor's prescription. If you feel that you might be suffering from depression, consult with your doctor to see if one of these medications may help.

MS and Mood Swings

Studies show that people with MS suffer from Bipolar disorder 15 times as much as the general public. People who suffer from this disorder experience mood swings which include an expansive, elevated mood, feeling on top of the world, alternating with depressive feelings. They may act egotistically, as well as have boundless energy and even agitation. Even after a mild frustration, hyper-irritability can result in an uncontrollable response, including rage. Relationships with family members and friends may become difficult and may include rude, argumentative or even abusive behavior. They may be action-oriented and impulsive. They can be thin-skinned in response to the mildest criticism. This is a very frightening experience which has been described by one sufferer as "the invasion of the body snatchers." Once again, if you or someone you care for has these MS symptoms, you should see your doctor and discuss a medication to help stabilize mood and increase a sense of well-being.

Anger

The hardest mood to control is anger, and emotional flooding is defined as a "susceptibility" to frequent emotional distress: of being swamped by dreadful, out-of-control feelings and thoughts. One cannot "hear" without distortion or respond with a clear head. It is hard to organize thinking. Many people with MS have a low threshold for flooding and family members ask what they can do to help. In his book "Emotional Intelligence: Why it Can Matter More than IQ," Daniel Goleman gives several suggestions to alleviate and control anger.

To defuse anger, we should strive to undermine the convictions that are fueling the anger in the first place. We know that the sense of being endangered is a universal trigger for anger. Also, symbolic threats to self-esteem or dignity, being treated unjustly or rudely, being insulted or demeaned, or frustrated in pursuing an important goal are anger triggers. One of the most potent ways to put anger to rest is to reframe the situation more positively in order to correct the misperception that, for example, one is being insulted. When the body is primed by anger, adrenocortical arousal causes a hair-trigger condition to occur, with anger then building on anger.

Challenging the thoughts that trigger the surge of anger is more effective the earlier the intervention. Anger can be completely short circuited if the mediation comes before the anger is acted upon. Physiological "cool down" is possible by waiting out the adrenal surge, in a setting where there are not likely to be further triggers for rage.

At the first sign of an argument:

- **get away** by yourself for the time being
- **seek distractions** (TV, movies, reading) to "brake" the anger and stop it from escalating
- take active **exercise** or a long walk to promote the deep breathing and muscle relaxation which changes the body's physiology from a state of high arousal to low arousal
- **write** down angry thoughts as they arise and challenge them later
- **after cool down** - discuss the dispute with the other person.

We have learned that giving vent to anger simply prolongs the mood. Family members or friends can help by maintaining calm body language. Anger is infectious: resist taking it personally. You can help to soothe the distressed feelings by showing attunement with them. Accurately mirroring the feeling of being insulted or frustrated contributes not just to

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feeling understood, but actively and meaningfully demonstrates emotional attunement. Let the person know you can see things from their perspective, that their point of view has validity. It helps to recover more quickly from the emotional flooding.

Remember:

1. Time out
2. Check your pulse rate
3. Distraction or exercise
4. After a 20-minute minimum discuss the conflict

Conclusion

The loss of emotional control in MS is often the most embarrassing, and most damaging to relationships, of all MS symptoms. Even though it may be difficult, it is important to talk to your close friends, family and physician about these symptoms and work together to alleviate the emotional storms and create a safe harbor for your physical, emotional and spiritual well-being.

> Some people wait all day for 5:00 pm, all week for Friday, all year for the holidays, all their lives for happiness. Don't be one of them. Don't wait until your life is almost over to realize how good it has been. The good life begins right now, when you stop waiting for a better one. – Author Unknown

Continuing Through May 2016

MS Wellness Education Classes

Please join MSSP and Paula-Noel Macfie, PhD, for a series that encourages personal wellness through social, emotional, physical, intellectual, environmental, spiritual and nutritional lifestyle support.

Please contact the office to register by either calling us at 503.297.9544 or emailing programs@msoregon.org. We look forward to seeing you there!

Christmas Party Review

By Candyce Hayes

Something extra special happened at the Christmas party. The Spirit of the Season and the joy of the day's activities fell upon the room. People began clapping, laughing, singing and even dancing! Of the 24 Christmas parties I've organized for MSSP this was my favorite. Wait till you see what we're planning for the 2016 party. I want to send a "shout out" to the folks that donated their time and weathered the cold and rain just to make sure our guests had a great time. Marcia was awesome as the volunteer coordinator and MSSP staff members Ginger and Cathy worked hard to make sure everything went smoothly. The entertainment was fantastic and there were lots of fun door prizes thanks to the generosity of local businesses. Indeed we had a great meal, met new and visited with old friends and left with lovely memories of a fun time had by all.

In My Words by Laurie Thorp

Bodybuilding, gymnastics and teaching fitness aren't the first things that come to mind when you think about a person with MS, they probably would never, in most cases, be considered possible. Well those are things that I do and I have MS.

After being diagnosed with MS in January 2005 I had no idea what was going to happen. My first thought was "oh crap" as every expletive flowed through my head. I made a decision that I was not going to let this MS thing stop me. I decided that it is my "speed bump" all things will move full speed ahead, with occasions in which I must slow down a bit.

I competed in a fitness competition for my first time in 2003 and since I was diagnosed I have competed in NPC fitness twice and figure once. The dieting part really isn't fun but it is doable. When I competed in 2010 the competition went great, no problems, I placed first. The 2014 competition however, was a comedy of errors. I step on stage to do my fitness routine after waiting backstage for 30 minutes, re-warming up many times. Finally on stage, the routine is going well until half way into it the music fades, I do a shoulder shrug and a short time later my music is back on, but it kind of killed the flow. Then, a little later, I get on stage for the figure posing round in high heels with hot stage lights. My legs get a little spastic and my smooth, well rehearsed quarter turns got wobbly. I hold the poses the best I can and try to stay standing. Finally we all get to exit the stage when oops, down I go. Luckily I had made it behind the curtain first. Hey, all was good, I made it off the stage and didn't get hurt.

Being active has always been a part of my life, I just can't imagine not. I don't hide my disease, but also don't necessarily advertise it either. I have taught group fitness for almost 23 years and I am a member of Naydenov's "special abilities" gymnastics team. I did my second tandem skydive (20 years after #1) this summer on my birthday with my brother, David, as my tandem master. Best birthday ever. I even got to trade skydive stories with Shari Staten. We are considering doing it again together this time around.

Being both a fitness instructor and an RN, I have always, even before my MS diagnosis, truly believed that exercise and a good diet are the best medicine and that any kind of movement is good. I try to practice what I preach and encourage others to do the same.

In April 2016 I am planning on entering another bodybuilding competition. It is definitely a bigger endeavor than it was prior to my diagnosis, but I am always up for a challenge. I always train to win but honestly, just being on stage is a win to me.

WAYS TO SUPPORT MSSP

We would like to invite you to help support the ongoing efforts of MSSP to improve the lives of MS patients in Oregon and SW Washington. How? By shopping at Fred Meyer and linking your rewards card to your favorite nonprofit, MSSP!

Here's how it works:

- Link your Rewards Card to MSSP.
- Whenever you use your Rewards Card when shopping at Freddy's, you'll be helping MSSP earn a donation from Fred Meyer.
- At the end of each quarter, Fred Meyer will make a donation to participating nonprofits based on the accumulated spending of the Rewards Customers linked to each nonprofit.
- Fred Meyer will donate $650,000 each quarter via Community Rewards.

You can read more about the Community Rewards Program and learn how to set up your account here: https://www.fredmeyer.com/topic/community-rewards-frequently-asked-questions

We appreciate you and the generosity of Fred Meyer to help improve the lives in our community.

10th Annual MJN Slingball Tournament

Pacific City, Oregon

Coming up this June 24-26, 2016
Held at the Perlican Pub and Brewery

Come down and help support MSSP while also enjoying a great time at the beach. Register to donate, play or volunteer by going to www.slingball.com

Honorariums
There are many occasions when you want to say something special to a family member, friend or associate. Honorariums are a way to commemorate special occasions, birthdays, anniversaries, weddings, retirements, graduations or memorial gifts. Whatever the occasion, your thoughtfulness will be acknowledged immediately to the person you are honoring and to the family.

Make a Designated Gift
By supporting a MSSP client program 100% of your gift will be used exclusively for that purpose.

Workplace Giving and Matching Gift Programs
Many workplaces today offer the opportunity to make a donation. Contact Candyce Hayes at 503.297.9544 or candycehayes@ msoregon.org for more details.

All proceeds help fund programs and services that directly help those living with MS, their family members and caregivers in Oregon and SW Washington.

MARK THESE DATES

Event/Activity	Date	RSVP
Acupuncture Different Locations Available	Weekly	503.297.9544 ongoing
MS Wellness Education Classes MSSP Annex	Every 3rd Monday Thru May, 2016	RSVP not required 503.297.9544
MSSP Annual Picnic Oaks Park 7805 SE Oaks Park Way Portland, OR 97202	June 18, 2016	RSVP required 503.297.9544
10th Annual MJN Slingball Tournament Pacific City, OR (Oregon Beach)	June 24-26, 2016	Register to donate, play or volunteer by going to www.slingball.com
Weekly Art Drawing Classes Starting in March on Mondays in the MSSP Annex Contact us at 503.297.9544 for more info	March 7 - April 11	RSVP Required 503.297.9544
Check out our website for updated programs at www.msoregon.org		

While we've got lots of medical equipment in storage there has been an unusual demand for manual wheelchairs. If you know anyone with a chair to donate please have them contact us.

ANNUAL PICNIC

Date:	6/18/2016 **MARK THE DATE!**
Location:	Oaks Park 7805 SE Oaks Park Way Portland, OR 97202
Time:	11:30am-1:30pm (lunch served from 12:00-1:00)
Cost:	*FREE "Donations Appreciated"*
Limit each party:	4 per family
RSVP Deadline:	6/12/2016
Call or Email:	503.297.9544 events@msoregon.org

FREE FROM FALLS

A COMPREHENSIVE FALL PREVENTION PROGRAM FOR PEOPLE WITH MS

VA Portland Health Care System

VA HEALTH CARE | Defining EXCELLENCE in the 21st Century

Comprehensive Fall Prevention and Detection in MS

Dr. Michelle Cameron, a neurologist at the VA Portland Health Care System, is recruiting for a research study to explore the effects of two methods of fall prevention on reducing falls in people with Multiple Sclerosis.

If you would like to participate, you must:

-Be over the age of 18
-Have Multiple Sclerosis
-Have fallen at least two times in the last two months
-Be able to walk at least 20 meters, with or without a walking aid
-Some participants will be asked to wear a fall detector during part of this study.

Participants will be randomly placed into two groups. One group will participate in an educational and exercise class on fall prevention; the other group will receive educational materials about fall prevention, and will be invited to take the class after the study is completed. In addition to class time, participants will come to the VA Portland Health Care System for four assessment visits over an 8-month period. You will also be asked to keep a daily record of your falls for this time.

This is a randomized trial. Half of the subjects will take the classes during the study, and the other half will be wait-listed and given the opportunity to take the classes after the study is completed. This is a research study and not treatment.

Some people in this study will also be asked to wear an automated fall detector for part of the study. This fall detector will record any falls you may have during the study, and the location where the falls occur. This part of the study is being conducted by Oregon Health & Science University.

Potential benefits include: aiding in scientific discovery and receiving training that may reduce your falls. Participants will be paid up to $80, if they complete the study. People who wear the fall detector will receive an additional $100, for a total of $180 for completing the study.

If you would like further information about this study, please contact:

Andrea Hildebrand, Research Coordinator **(503) 220-8262 x52016**

VA Portland Health Care System – Portland division / 3710 SW US Veterans Hospital Road / Portland, OR 97239VA

VA IRB 3516 / OHSU eIRB 11805
Version Date 11/19/15

APPROVED: Dec. 10, 2015

IMPORTANT MESSAGE

We have exciting news! Effective June 1, 2016 we are switching from printed to online issues of our quarterly newsletter. Not only do we save money YOU will be kept updated about programs and other issues of interest to the MS community. Up until now many opportunities are omitted because they didn't fit into the printing schedule. Soon we can send you updates.

To make sure you don't miss out we need your email address. We realize not everyone has access to a computer or may prefer to receive a printed copy of the newsletter so we will have a limited number of printed copies. If that is you let us know by calling the office at **503.297.9544**. Rest assured your address will be held in strict confidence. We do not share our list with anyone.

Please take a moment to send us your preferred email address that you would like to have newsletter alerts sent to **programs@msoregon.org**. Please put "newsletter alerts" in the subject line.

Please note that this is our final printed version with exception of ones that will be printed and mailed out to doctors' offices.

Thank You,
Candyce Hayes
Executive Director

MSSP PROGRAMS & SERVICES

EQUIPMENT CLOSET

Our healthcare system limits the kind and type of medical equipment a client can get. For instance, insurance will pay for one wheelchair (manual or motorized) every five years. Meanwhile the client's MS symptoms may have worsened. To address this need the MSSP has a free medical equipment closet of new and refurbished equipment. The closet contains manual and motorized wheelchairs, scooters, canes and other various types of products. All requests must be accompanied by proof of MS diagnosis and recipients must live in Oregon or SW Washington.

ACUPUNCTURE

Offers Symptom Relief

MSSP, thru its partnership with local acupuncture centers, provides stipends to help offset the cost of one hour visits. Clients pay $10 per session and the MSSP pays $15. To ensure you receive the maximum benefits we ask that all participants commit to weekly visits over a 6-month period.

PROJECT HELPING HANDS

To provide comfort and stress reduction

Now you can receive up to four discounted 60-minute sessions with a licensed massage therapist (LMT) either at their office or at your home for just $10 per visit! The MSSP pays $20 towards your session. Project Helping Hands is meant to provide comfort and stress reduction - it is not meant to represent or replace physical therapy. These sessions (visits) may occur weekly, bi-weekly or monthly depending upon your needs and the volunteer LMT's schedule.

SUMMER COMFORT

New air conditioners for individuals with MS

Now you can get relief from the hot summer temperatures. The MSSP offers new, free, portable window air conditioners to individuals diagnosed with MS living in the state of Oregon and SW Washington. Units are given on a first-come, first-serve basis and awarded as funds are available.

OTHER PROGRAMS & SERVICES

To access any of our services or programs, call 503.297.9544 or email us at programs@msoregon.org

MSSP

Multiple Sclerosis Society
of Portland, Oregon, Inc.

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 _________

My Contribution is for:

☐ Client Emergency Fund
☐ Summer Comfort
☐ Caregiver Classes
☐ Social Programs
☐ Medical Equipment
☐ Greatest Need

My Name: ______________________

Address: ______________________

City/State/Zip: ______________________

Email: ______________________

Phone: ______________________

If you would like to send this gift in honor or remembrance of someone, please include a note with their name & address or if applicable, the name of whom we should send acknowledgement to with their address.

Please clip this form and mail with check payable to MSSP:

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