

MULTA SPES

MUCH HOPE

IMPROVING THE QUALITY OF LIFE FOR THOSE WITH MS SINCE 1949

Winter 2011-2012 Issue

Director's Notes: by Candyce Hayes



I hope the upcoming holiday season is memorable and joyful. For some, however, the holidays are full of dread due to past disappointments and future expectations. For these reasons we've dedicated this newsletter to help you deal with emotions. I hope you find it useful.

In the meantime, remember to breathe and take things one project at a time. Consider attending the annual Christmas party (see page 7 for details). Seating is limited and we expect a full house. Robbie Laws will be our special music guest. Best wishes!

Sharing Feelings A Professionally led MS Support Group

"Sharing Feelings" is a professionally led support group offered to MS patients, their families, and their caregivers. This group provides a supportive and constructive arena to share feelings, explore avenues to self-challenge, self-help, or acceptance, and to facilitate open and clear communication.

While the participants are all connected in their experiences associated with MS, and many of the concerns that arise are MS related in some way, the group also deals with other not-specifically MS related issues. For example, topics that often come up include elderly parents, marital conflict, the challenges of travel, and parent-child communication. This group is facilitated by Sylvia Randall, Ph.D, a clinical psychologist who specializes in working with adults, couples, and families. Five years ago, her husband Steve was diagnosed with MS. Through this journey with him, she has become intimately aware of the numerous challenges and life changes – the losses involved, and the occasional unexpected gifts. All of these primarily affect the individual with MS, but they also deeply affect family, caregivers, and co-workers.

This group meets at 12:00 noon on the last Thursday of every month for 90 minutes. There is no charge.

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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: 1/15/2012.

Please send submissions to Candyce Hayes, Executive Director, at: candycehayes@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 candycehayes@msoregon.org or call 503.297.9544.

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Poem *By* Donielle Brown

The Answer

It's here,
the answer I've been waiting so long for.
It may have come in a very unexpected form,
but it's an answer nonetheless.
Multiple Sclerosis means, "many scars",
they come in forms other than
just those it's defined by.
This disease, this "answer"
affects you from head to toe,
on the inside and out.
It also touches those you love
and those who love you.
I think what's most amazing is that these "scars",
the "scars" built up from the disease,
they aren't even visible on the outside.
They are silent attackers.
They hurt our bodies
and they hurt our minds.
They give us pain
and make us feel so uncomfortable.
And the worst part of it is,
that right now,
nobody knows how to make it go away.
There is no cure,
only possible, temporary, band-aids.
This answer was certainly
not what I was expecting.
I don't know what I was expecting.
I definitely wasn't armed and ready.
Sometimes I don't feel strong enough to tackle this,
this answer I had been waiting for.
I won't let it win.
I will take this one day at a time.
Multiple Sclerosis,
the answer,
not the end.

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 become less due to the physical changes in their brain.

A Toronto study in 1987 by RT Joffe 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, as written by Dr. Sarah Minden in her 1990 book. 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 – 60% of people with MS suffer from depression. This depression may be caused by their circumstances, or 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

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Riding The Storm *Continued*

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. 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) 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

The Toronto study noted earlier showed 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 trial to help stabilize mood and increase a sense of well-being. Medications that can be used for this disorder include Depakote, Lithium and Clozapine.

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: In Daniel Goleman's book, "Emotional Intelligence: Why it Can Matter More than IQ", he gives several suggestions how 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

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Riding The Storm *Continued*

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 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.

MSSP wraps it up



How’s your gift wrapping skills? MSSP has an opportunity to collect tips for wrapping gifts at the Clackamas Town Centre’s Barnes & Noble store this holiday season. Volunteers are needed on November 25 & 26 & December 15 & 16. If you’d like to get involved please call the office at 503 297-9544 for more details.

KEEPING OUR DOORS OPEN:

2012 ANNUAL BENEFIT CONCERT BLUES FOR MS II

We are excited to announce the second annual Blues for MS concert will be held at the historic Roseland Theater in Old Town Portland Sunday March 4, 2012 from 3pm to 9pm. B4MS II will be the largest 'free' concert of the year (but of course donations will be gladly accepted).

We are even more excited as the best Blues bands around will be performing at B4MS II including:

- The Robbie Laws Band (One of our all time favorites). Robbie will also be performing at our MSSP's Christmas party.
- The Duffy Bishop Band. Duffy is one of the most beloved artists in the northwest and an absolute crowd pleaser.
- Boogie Bone, one of the great up and coming bands. Many of their loyal fans, known as 'The Boneheads' will surely be rooting the band on.
- Chad Rupp & The Ruppshakers and AC Porter & The Live Wires. Two of the Muddy Award's 'Best New Act'.
- Randy Oxford will finish out the night. Randy is one of the NW's most popular acts and gave Buddy Guy a run for his money at last year's Waterfront Blues Festival.

Just prior to the concert both Robby Laws and Randy Oxford will be returning from Memphis where they will be representing the NW in the 28th annual International Blues Challenge.

In addition to this great lineup, Dave Dahl of Dave's Killer Bread fame will say a few words and then perform the 'Blues Bun Blues'.

Now a few words about two of the items in the B4MS II Raffle:

- An Eric Clapton Signature Model Fender Stratocaster valued at \$1,600. Stay tuned as we are working with Fender Music's Artist Relation folks to see if we can get EC to sign the guitar.
- A wonderful Martin 00-15 acoustic guitar made in Martin's Nazareth PA's factory valued at \$1,400. The 00-15 is an authentic blues-type guitar reminiscent of small-bodied Martins of the 1930's. Favored by legions of blues players.

So set the date of March 4th and come join in the fun and listen to some of the best bands around.

Mark These Dates

Event/Activity	Description	Date	RSVP
Acupuncture	Monday drop-ins at MSSP	On-going	Please call the MSSP office for more details 503.297.9544
Acupuncture	Saturday by appointment only	On-going	To schedule call the MSSP 503.297.9544
Christmas Party Montavilla United Methodist Church	Special Musical Guests: Robbie Laws & Friends	12/10/11	RSVP required by 12/2/11 <u>Space Limited</u>
Blues For MS II Roseland Theater 8 NW 6th Ave Portland, OR 97209	Seven Blues Bands from 3:00pm - 9:00pm	03/4/12	Free with donations accepted at the door for more info see: www.blues4ms.org

FYI

Sharps Containers

We have a limited amount of empty sharps containers for your used MS drug needles. They will need to be picked up at the office. For more information contact 503 297-9544.

CHANGES CHANGES CHANGES

Saturday acupuncture is now “by appointment only”. Please call the office by Fridays at 12 noon if you wish to attend.

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 - <u>Space Limited</u>
RSVP Required:	Deadline: December 2nd
Call or Email:	503.297.9544 events@msoregon.org or register online at www.msoregon.org/calendar.html



Multiple Sclerosis Society
of Portland, Oregon, Inc.
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Portland, OR 97236

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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 _____

My Contribution is for:

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

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.

My Name: _____

Address: _____

City/State/Zip: _____

Email: _____

Phone: _____

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