

MULTIPLE SCLEROSIS SOCIETY OF PORTLAND, OREGON

MULTA SPES

MUCH HOPE

IMPROVING THE QUALITY OF LIFE FOR THOSE WITH MS SINCE 1949

Director's Notes *by Candyce Hayes*

A picture hangs above the main door entrance proclaiming, "Each Day Is a Gift". The living room curtains are hung. The bathroom has been stripped to the bare wood frame. Within days the new walls and floor will be installed. The next MSSP house remodeling project to tackle is finishing the driveway modifications. Like many great things—the MSSP house remodel is taking shape - slower than anyone could have ever imagined or anticipated. Please be patient just a little longer.

Speaking of anticipation – **I learned** some amazing things I want to pass along with you. The lessons came as a result of my recent cross country road adventure (actually half-cross country. I rode as far as Cedar Rapids. Another friend joined Christine in Iowa for the last leg of the journey).

The story begins when my friend, Christine, accepted a new job in North Carolina. She had to **drive** from Portland rather than **fly** because her 6-year old, 75+ pound Rottweiler mix dog, named Owen Arthur, refuses to fly. I volunteered to ride along, share the drive and keep her company. **Life is funny** - this opportunity arose at the tail end of a long illness. For months my life seemed like a never ending cycle of going to the doctor, picking up prescriptions and attending therapy. Frankly, **I wasn't sure I was up for the trip** when I made the initial offer. I knew a **vacation budget** was **non-existent**. At the same time my spirit yearned to break the cycle - I wanted and needed a new adventure!!!

The first day of our drive from Portland to Missoula was uneventful. Day two, we landed in Jackson Hole Wyoming – gosh what pretty country! I had no idea Wyoming was so darned *w-i-n-d-y!* During a pit stop we discovered the official "Fireworks Store and Laundromat" (all under one roof mind you). Sadly this unique business venture must have failed based on the large, cob-webbed "for sale" sign. The Grand Tetons were majestic. The sun cast a stunning pink and blue hue on the mountain range that left me breathless. Day three, we stayed overnight with Christine's friends, Sarah and Dan, in Denver Colorado. Wouldn't you know it? Sarah's mom has MS. Over dinner we talked about her Mom's challenges. I offered ideas and suggestions. The next morning as we approached the outskirts of Denver, Christine says "Ok, now look at the map and tell me which road to take." I don't know where it came from but I snapped, "No! – I'm tired of reading maps – I won't do it – I won't do it." After all, my offer to BUY maps was by no means an indication I actually "knew" or ever wanted to "read" a map. Christine began shouting, "You can do it Candyce – you can do it. Tell me which road to take!!!!" I glanced up to see no less than 10 large green signs looming ahead. I recited a silent prayer, took a deep breath and with full confidence replied, "Go east – go east". We headed east. A long, awkward silence fell upon the car for the next 30+ miles. Even Owen Arthur was quiet. Whew, well I made the right choice! Next stop, as Christine called it, was, "Stinkin' Lincoln

Nebraska". What stands out in my memory was the "Pump, Church & Pantry," – now that's really one-stop shopping! That evening a nice hotel desk clerk gave us a break on our room since the only thing available was next to the swimming pool. As we checked in we thought—"big deal so we smell a little chlorine!" Upon returning from dinner and eager to rest, we discovered a swimming pool full of hormone-driven FFA teens! Yes they were having a grand old time – yelling, hollering and flirting with the gals. Owen Arthur cocked his head as if to say, "...and

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Multa Spes is the quarterly newsletter of 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 8/1/2006 and 10/1/2006.

Please send submissions to Candyce Hayes, Executive Director, at: candycehayes@msoregon.org or Mail: MSSP, P.O. Box 16553, Portland, OR 97292-0553.

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.

Advertising in Multa Spes does not represent an endorsement of any product, service or individual by MSSP, its staff or Board of Directors.

Each advertiser is solely responsible for the accuracy of their advertisement and for any claims, loss, damages, and liability that may result.

Director's notes continued

they charged a pet fee, I wonder if their parents had to pay a "teen fee?" Oh well.

The dry, flat, Nebraska landscape was broken only by the occasional full sized, green, John Deere tractor sitting 300 feet in the air! Mid-morning of the fifth day we arrived in Iowa. By using my frequent flyer miles to return to Portland we figured it cost less than filling her car tank once!

Granted Iowa may not yet be a world-class vacation destination, I had a blast. Meeting new people, visiting new places felt so good. **The lasting gift was the awareness that "positive anticipation" can and does fuel the mind/body/spirit with renewable energy that can be applied towards balancing home, work, health and other life-issues. So be willing to take a chance, grasp opportunity as it arises and create new, fun, events and activities to enjoy.**

Wheelchair Batteries MK Battery

When I contacted Tom Coogan, our good friend at Care Medical, with my concern about using a car battery to **replace a nonworking scooter battery, he strongly recommended against it.** Tom arranged for someone at MK Battery to email us the following article. **If you have any questions or need more information about replacing wheelchair or scooter batteries, Tom encourages you to call him at 503 288-8174.**

Batteries are one of the most unpopular subjects in both the DME (durable medical equipment) and transportation markets. The fact is that while substantial technical changes have occurred in wheelchair electronics, control systems, and mechanical drives over the past 20 years, batteries have undergone only one significant change - the advent of high quality gel/sealed batteries.

INDUSTRY HISTORY AND THE PRODUCTS

The history of power mobility equipment has always included the "Deep Cycle" battery. The "Deep Cycling" technology, unlike that of automotive starting batteries, allows us to charge and discharge a battery on a constant basis. This ability to be a "FUEL TANK" is exactly what the wheelchair systems needs.

Consumers, with all of their different lifestyles and equipment needs, place

serious demands on batteries which only "Deep Cycle" products can meet. "Deep Cycle" products have been the only viable alternative for wheelchair users by providing a consistent reusable fuel source.

The "Wet" style "Deep Cycle" battery, commonly known as a "Lead Acid" battery, was the standard as a wheelchair battery for many years. This is the battery most people are familiar with for better or for worse. As a fuel tank this product has proven a reliable source of power as long as it is properly maintained. Their basic design has changed little over the past number of years.

A newer class of "Gel/Sealed Lead Acid" batteries has been gaining in acceptance for the mobility application and has, in fact, become the standard for mobility equipment use. While early versions of these products were not acceptable for "Deep Cycling" applications, products with comparable "Deep Cycling" have become a variable over the past few years. New technologies, manufacturing techniques, and a better understanding of charging requirements now allow these products to be used quite successfully in wheelchair systems. Both battery types share some common features:

1) Both are hazardous materials since they contain "Lead" and "Sulfuric Acid"

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Wheelchair Batteries

2) Both produce energy by the same chemical process.

3) Newer “Gel/Sealed” batteries have virtually the same capacity (the level of energy storage) as “Wet” batteries, a major limiting factor in older styles of “Sealed” products.

There are some **critical differences** between the **two types** of products that affect all of us involved in the mobility field. These differences directly apply to **safety, maintenance, transportation and cost-effective application.**

WET BATTERIES

“Wet” batteries **require regular monthly maintenance** to maintain electrolyte levels. Battery electrolyte is the acid/water mixture found in batteries. **Replacement of water is necessary on a regular basis** because **water is constantly lost** during the charging process in a “Wet” type battery. **Too little electrolytes** and the **battery plates become damaged.** **Too much** and the **electrolytes** can be **forced out of the batteries through the vent system.** Not only will this affect performance of the batteries, it also allows electrolytes to escape into the battery box.

The “Wet” batteries’ **venting system allows battery electrolyte to escape** if the batteries are **tipped over.** The **venting systems allow built up gasses** during charging **to escape** yet they also allow fluids to pass as well.

Lastly, “Wet” batteries’ have **greater explosive potential** because of the exposed gases from charging. Hydrogen gas, produced during charging, is **highly flammable.** If electrolyte levels are low in a battery, there is more room for gas buildup and a higher risk of explosion.

The “Wet” battery’s one **major attribute** has been and continues to be its **initial cost**, usually about half that of a comparable size “Gel/Sealed” battery.

GEL/SEALED BATTERIES

1) Designed to be **permanently sealed** with venting under only severe overcharging conditions. The battery’s design allows the hydrogen and oxygen gases to recombine and form water, keeping all products internally in the battery. **(NOTE: If a “Wet” type charger is used on “Gel/Sealed” batteries recombination of gases may not take place fast enough and gases can be released!)**

2) Gel/Sealed batteries are **nonspillable in any position.** A number of wheelchair and scooter systems actually have batteries that are mounted with their vents to the side without risk of leakage.

3) One of the **greatest advantages** for wheelchair users is the fact that “**Gel/Sealed**” batteries are always **maintenance free** (Though we hasten to add maintenance free does not always mean sealed i.e., the maintenance free car battery, while not requiring water, may still use a venting system which will allow liquid electrolyte to escape. The one **drawback** to “**Gel/Sealed**” batteries is the **higher initial cost.**

Wheelchair and scooter manufacturers have been offering charging systems that will properly charge “Gel/Sealed” batteries for some time. This has occurred over six years throughout the mobility

equipment manufacturing industry, so a majority of the charging systems in existence are designed to be readily transportable. The primary customer group, the elderly, generally has a more difficult time with safely performing maintenance. As more customers become aware that a sacrifice of performance is not always automatic when changing to “Gel/Sealed,” we expect to see, as has been the trend, a continuing switch to these products.

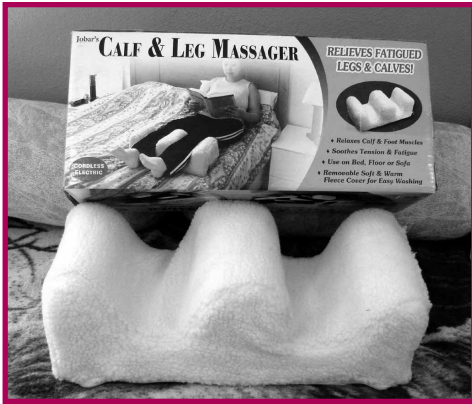
The single greatest obstacle to faster change is funding for the added cost of “Gel/Sealed” batteries and proper chargers. It is simply not available from government and insurance providers, the largest payers for power mobility equipment.

MSSP Newsletter Now Available On-line!

If you receive our quarterly newsletter delivered to you by mail, please let us know if you’d prefer to receive the newsletter by e-mail notification. Each quarter, you would receive an e-mail containing the direct link to download our newsletter (currently posted as a Microsoft Word document).

To subscribe to this e-mail notification list, send an e-mail to Candyce at candycehayes@msoregon.org containing your name and e-mail address, with “change format to e-mail” in the subject line or simply call us at 503-297-9544. Thank You!

Tips, Techniques & Tricks



Product Review Introduction

RC has struggled with leg pain for many years with little relief. Meanwhile MSSP regularly receives several medical and general merchandise catalogs. So knowing of RC's pain, MSSP staff ordered the calf & leg massager and asked RC along with another MS client to try the massager and share their opinions (see below).

Clients are asked to rate the product on a scale of 1 (not helpful) to 10 (fantastic).

CONCERN 1: Painful calves and upper legs.

ITEM: Leg and Calf Massager Works great on the bed or on the floor. Unique indents cradle your legs while the built-in massagers ease pain and stress away. Improves blood circulation, stimulates the internal organs, aids in restoring restful sleep, and renews vitality and health. Removable synthetic fleece cover is comfortable and easy to clean.

COST: \$39.98+ shipping/handling

BUY: Local Department stores in the prescription dept. Dr. Leonard's Healthcare Catalog
1 800 785-0880
EBay?

REVIEW: RC says "..... a solid 7 - there are things to consider. I even had limited short-term success with MSSP's massage program, "Helping Hands" therapy and ended that after about 4 sessions. I think the massager is a "10" for most folks, and don't forget the FOOT, as well - Mrs.RC has plantar fasciitis and loves the foot massager when she is walking or standing too much. I have pretty regular bi-lateral calf spasms and need to be careful to NOT put much, if any, pressure on them."

MS says, "6-7 which isn't bad for me".

CONCERN 2: I need help turning my legs when transferring from a wheelchair into my car.

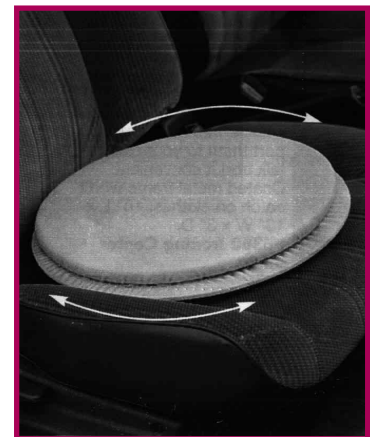
ITEM: Swivel Cushion
This 15" cushion swivels a full 360 degrees to glide in or out of a car. Eliminates stressful twisting, reduces strain on back, hips, neck.

COST: \$19.98 + shipping/handling

BUY: Make Life Easier
1 800 522-0227
Dr. Leonard's Healthcare
Catalog 1 800 785-0880

REVIEW: JJ says, "it's a 10! I'd be lost without it and an added bonus is now I sit higher in my seat too".

If you will share your challenges, needs, concerns (requests MUST BE in writing via attached form (page 5) and returned by mail or go to our website to apply). MSSP will go to work looking for items/products that may help.



PLEASE JOIN US

WHO:	All MSers, family members & friends
WHAT:	Fall MSSP Social
SPEAKER:	Janet Braham, RN
TOPIC:	Latest developments in MS Treatment
WHEN:	Saturday, September 23, 2006
TIME:	11:30-3:30 (NOTE NEW TIME)
WHERE:	Rose City Park United Methodist Church 5820 NE Alameda St., Portland
BUS LINES:	Tri-Met 1/2 block away #12 & #71
RSVP DATE:	September 21, 2006
RSVP TO:	503 297-9544 or events@msoregon.org
SURPRISE:	Candyce Hayes

Year to Date MSSP Program Reviews

During May's "MS & Sexuality" workshop OHSU Associate Professor, Jillian Romm led a small but intimate group through a very thoughtful and informative meeting where they discussed concerns, received suggestions and other practical and useful information. Tom Coogan's presentation about community resources was exceptional.

BINGO BLAST

This was Sharon's first MSSP Bingo party. She met new friends and won the door prize of \$325 in gift certificates redeemable at any Shilo Inn too!

(Some folks asked why we gave one big door prize versus splitting up certificates. The answer: We wanted the winner to have the option of using the gift during a weekend or breaking them into smaller stays.). Meanwhile the bingo prizes (gift certificates at local stores, restaurants and video store rentals) were a big hit!

Perfection is the best way to describe the June 17th annual picnic at Oaks Park. Nearly 150 guests enjoyed an afternoon of friendship, fairway games, rides and

food. Thank you, Nancy Palmer, and our friends from Serano for sponsoring this and the 2007 MSSP picnic.

Dog (and puppy) lovers welcomed and oriented Tyson during his debut as a service dog! Tyson, my newest 3 month old Yorkie puppy, snuggled up and played the day away. Tyson's mate, Tessa, was born July 7th and may attend the September 23 MSSP get together.



Sally and Tyson pose for a picture



Tyson & Bill eagerly await that first bite of fried chicken!

MEDICAL EQUIPMENT CLOSET

Have you been turned down by your insurance company for needed medical equipment? If so, call 503 297-9544. MSSP has a free medical equipment closet consisting of donated, used, or nearly new equipment – **Note MSSP does NOT carry bath items (like shower benches, commodes) due to hygiene-related issues.**

FYI

WINTER UTILITY RELIEF - Funds through the LIEP (Low Income Energy Assistance Program) go fast. Mark your calendar for October 1, 2006 and depending upon the county where you live call: **Clackamas, Multnomah, Washington, and Yamhill Counties – LIEAP**

- Dial 211 (Community Information & Referral Line).
 - o Dial 503 222-5858 if 211 are not available in your community.
- An applicant's household income must be at or below 60% of the Oregon Median Income.
 - o For a household of one, this was \$18,802 per year in 2004; for a household of four was \$36,157 (updated information not available until mid-September 2006).

Washington (Clark County) —LIEAP

- Contact Clark Public Utilities at (360) 992-3000 to see if you qualify for energy assistance.
- Customer service representatives available seven days a week, 24 hours a day via phone.
- You will be required to provide your:
 - o 11 digit account number from a recent bill
 - o Social Security Number
 - o Zip Code
- If you qualify, you will be directed to contact:
 - o Call 1-866-861-6354 to schedule an appointment
 - o Automated line opens at 9am, weekdays only
 - o Limited number of appointments available each day
 - o Appointments are scheduled for 2 weeks after call

HEAT RELIEF – it's not too late to apply for a portable window air conditioner thru MSSP's "Summer Comfort" program. For more information, call 503 297-9544 or download and submit an application form directly from our website at www.msoregon.org.

Don't forget about other cooling aides that can make life easier: tower fans range from \$30-\$40. Many models offer remotes. A swamp cooler is an affordable alternative to a portable room air conditioner (\$400-\$700). Both items can be found at most local hardware stores and range in price from \$35-\$150.

Cooling vests and other clothing items can be purchased from these companies:

Cool Tek 1 888 849-3657 or
 Info@HeatRelief.com
 Air Gas Direct 1 800 827-2338

The Art of Listening

How well do you listen to others? Good communication is critical to all relationships. When you live with a chronic illness – **faulty communication could be fatal**. Today we're going to focus on half of the communication process; **listening**.

A good listener is appreciated by just about everyone. By listening well, we can refresh people who are distressed or loaded down with problems. Unfortunately too many people are poor listeners. How can we learn to improve our listening skills?

Ideally **set a time and place** to discuss important issues. **Eliminate potential distractions**; turn off the television, put down the newspaper or turn off the cell phone when someone asks of you about a serious matter. **Get comfortable** – it's hard to pay attention if your feet hurt or you need a drink of water. As you begin listening, **resist** the temptation to **start talking about yourself** or offering comments like "that reminds me of what happened to me some time ago." While such an exchange is

acceptable in a friendly conversation, we need to put personal interests aside when someone is discussing a serious problem.



Listener's Body Language

It takes discernment to draw a person out. **Asking questions is always** helpful but be careful that your questions **do not pry** into private matters. **Inviting the person to begin with matters** he/she feels comfortable mentioning is a good way to get started.

As the person begins talking the **listener should maintain eye contact**. **Leaning forward** shows your concern for the other person's feelings. **Do not judge** the **person** or **situation**. Making **sympathetic comments** like, "that must have felt _____" is one way to show your concern.

Another way is to put what the person is saying in your own words (**paraphrase**), thus showing that you understood what was said. Listening **requires paying attention** not only to the words, but also to the **emotions subtly expressed**.

Can we listen without agreeing with what is being said? Can we say to someone that we appreciate being told how they feel? **Yes**. Listening when someone is upset can be challenging – especially if the person is upset with you. The natural inclination is to defend yourself. So how can we meet this challenge? **Kindly** invite the person to talk — and then patiently

listen as he/she expresses their grievance is one way to reply with kindness. **Heated arguments** often consist of two people merely **repeating what they have already said**. Each one feels that the other individual is not listening. How good it would be if one of them would stop and really listen! Of course, it is important to **exercise self-control** and express oneself in a **discreet and caring way**.

The ability to become a good listener **does not come naturally**. It is an **acquired skill** that requires **effort** and **discipline**.

KEEPING OUR DOORS OPEN

Kate Simonsen (as seen in image to right; center) has personally dealt with MS for many years. Last year Kate and friends raised over \$700 to help MSSP. This year 20 families are joining her efforts. Please show your support by attending (and buying) a new treasure at Kate's garage sale.



Candyce Hayes, Kate Simonsen &
Kristina Kutrz (2005)

*Kate's
Garage Sale
time!*

**Saturday only
September 16**

3925 SW 78th Ave.-Portland

**All proceeds benefit the
MS Society of
Portland, Oregon**

Recent Client Program Grants

MSSP relies on volunteers, private contributions, donations from companies of products, supplies, etc., fundraising events and grants to support its programs and services. Recently MSSP was given the following support:

Biogen, \$2,000 – Gentle Yoga program

MS House

Fabric Gallery – Patty (owner) donated her time to help make beautiful living room window treatments for MS Resource Center.

Sue Schnepf, an interior designer, donated her skills to help us create a warm loving atmosphere.

Serono – donated three ADA toilets.

Mattress Factory Outlet (Vancouver)– Donated and delivered 8 twin adjustable bed frame/box springs with remotes and 1 mattress.

LOST MAIL

Please **ALWAYS** use the **MSSP Post Office Box (16553, Portland, OR 97292-0553)** address when contacting MSSP. Apparently despite several requests, the post office won't forward mail sent to our old Westgate address because we moved nearly two years ago. Thus some client applications, correspondence and gifts are being lost in the mail. MSSP **relies** on private **support** to help those **living with MS** so please **discard** any thing with the **Westgate address**.

MSSP **MAKING LIFE EASIER** APPLICATION

Mail to: POB 16553, Portland, OR 97292-0553

CLIENT NAME: _____

ST ADDRESS: _____

CITY, STATE ZIP: _____

EMAIL: _____

TELEPHONE: (H) _____ (W) _____ (C) _____

DATE MS DIAG: _____

PROGRAM GUIDELINES

MSSP seeks to offer suggestions, ideas and products that may help to manage MS-related symptoms; (pain, increasing mobility issues, etc) and/or make every day tasks easier for those living with or affected by Multiple Sclerosis.

Describe your challenge: _____

How have you tried to manage this issue in the past? _____

Are you willing to sample (and provide report) on an item/product? Yes ___ No ___

If Yes:

I agree that neither the Multiple Sclerosis Society of Portland, Oregon, Inc, (MSSP), its agents, employees, and/or volunteers shall have any responsibility or liability associated with my use of any and all provided product(s).

Client Signature

Date

Multiple Sclerosis Society
of Portland, Oregon, Inc.
P. O. Box 16553
Portland, OR 97292-0553

Multiple Sclerosis Society
of Portland, Oregon, Inc.
P. O. Box 16553
Portland, OR 97292-0553

PLACE
POSTAGE
HERE

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 \$25 other _____

My Contribution is for:

- | | |
|--|--|
| <input type="checkbox"/> Membership Dues (\$20.00) | <input type="checkbox"/> Social Programs |
| <input type="checkbox"/> "Project Connect" | <input type="checkbox"/> Medical Equipment |
| <input type="checkbox"/> "Project Helping Hands" | <input type="checkbox"/> The Greatest Need |
| <input type="checkbox"/> "Summer Comfort" | |

I am (please check one):

- MS Patient Caregiver Family/Friend Friend of MSSP

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 acknowledgment to with their address.

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

P. O. Box 16553 Portland, OR 97292-0553

Time Dated Material

NON-PROFIT ORG.
US POSTAGE
PAID
PORTLAND OR
PERMIT NO 829

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of Portland, Oregon, Inc.
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Portland, OR 97292-0553