

Directors' Notes: by Candyce Hayes

I'm about to date myself. Do you remember the old television show, "Naked City?" Elliott Ness was the primary character. Each week he fought crime and the mob. I fondly remember the feel of the old mohair couch as I sat perched, awaiting those magic words, "*There's a million stories in the Naked City.*" And like those stories of yester year, here's one of many "MSSP stories."

Monday morning I check the telephone messages left over the weekend. I find an urgent message from a worried mother (Judy*) in Mississippi. Her 25-year old son (Don*) moved to Portland three weeks ago. He was hospitalized over the weekend with an MS attack. Don is facing a housing crisis. He can't drive since his feet now tingle. He doesn't know Portland freeways. She's 2000+ miles away and doesn't know where to turn or how to help. Over the next few days I work with Judy, Don and an MSSP volunteer to get everything settled. Six days later Don is moved. Judy can take a deep breath thanks to MSSP and a caring volunteer named Tim*.

Since 1949 MSSP has had many "Elliott's and Ellie's" fighting the crimes of loneliness, ignorance, poverty and despair. With their help, MSSP has met needs, such as donating used scooters (\$1,200 avg.), manual wheelchairs (\$500 avg.) or new portable air conditioners (\$175 avg.) to battle the devastating effects of heat each summer.

What's amazing is that over 80% of MSSP's support comes from private individuals. Please join these heroes today by making a gift to MSSP. Every contribution goes directly back into our community to support people like Judy and Don.

*names were changed to protect confidentiality



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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 8/1/2008 and 10/1/2008.

Please send submissions to Candyce Hayes, Executive Director, at: candcyehayes@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 candcyehayes@msoregon.org or call 503-297-9544.

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Vacation Cruises Treat Guests Like Royalty

by Alan Roth (via Ken Levy)

Are you thinking about taking that ultimate vacation on a luxury liner to an exotic location? "Well expect to have a great time and a fantastic on-board experience" says our experienced cruisers, Linda and Alan Roth. Last year they completed their second boat cruise.

"We sailed seven days to Puerto Vallarta. On the way back we sailed to Mazatlan and Cabo San Lucas via the Princess Cruise Line's "Sapphire Princess," said Alan. The Roth's' recommend the adventure for anyone traveling with or without wheels (Alan is confined to a wheelchair). For the greatest enjoyment and flexibility they recommend traveling in groups (they were part of a group of 16 on this particular voyage).

"My wife is my caregiver. She totally dedicates her time to taking care of me. Any chance I get I let her go on vacation. The people with us recognized this and pitched in to take over some of Linda's caregiving duties which gave her a much-deserved vacation as well. Once you're on a cruise ship, if you're in a wheelchair, they find a handicapped room for you, which is generally larger than the others," Alan said.

The Roth's room became the gathering spot for their entire group. "We had a balcony so I could get out and enjoy the cool evening breezes. I enjoyed sitting and watching. The cruise line staff was extremely attentive and saw to our every need. In fact, we were treated like royalty!"

At some stops the group went ashore but was concerned about Alan being alone on ship. "Don't worry about me! There's so much help on a boat that you can go anyplace you want and, if you need something, just say it and they bring it to you. I really enjoyed that time alone."

Alan did go ashore at one port. "Going ashore, one realizes just how good you have it on board. It's easy to come to expect the same selection and service anyplace you go (off boat) but you don't get it." Simply put, the food selection and service was flawless.

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Vacation Cruises Treat Guests Like Royalty (Continued)

The weather played an amusing part in this voyage. "As we got into Mexico, it was like the clouds from the Pacific Northwest followed us there," Alan recalls. We noticed a lot of people who expected to spend their vacation by the pool in Mexico working on a suntan but no such luck!"

A few ports, roads and sidewalks were awkward for wheelchair people, meaning extra work "for people who are getting you around. There's never a dull moment on board. The ship features numerous restaurants and lounges and nightly, Las Vegas-style live entertainment with 12 (or more) floors. You could pick a floor and go gambling, smoke cigars or get into the pool, sauna or workout room. They even have classes on computer programs. If there's any doubt about going on a cruise, "trust me you will enjoy yourself so much that there will be no doubt, you'll want to go back. When you start feeling what the real world is like again, that's when it hits you."

FYI

After 15 years in NW Portland the Taoist Tai Chi Society of the USA, Oregon Branch, has moved to: 2505 SE 11th St. (at Division), Suite #120, Portland, OR. This internal health training seeks to help improve circulation, balance and posture; increase strength and flexibility along with the reduction of stress. With regular practice, the Taoist Tai Chi(R) internal art of taijiquan reaches deep inside the body to benefit the entire physiology including the tendons, joints, spine, connective tissue and internal organs. It restores the calmness and peace of mind that is often lost through the desires and anxieties of daily life. For more information, please contact us online at <http://oregon.usa.taoist.org/> or call 503-220-5970.

Magnetic Helper

If you're like me dropping your keys on the floor when alone can be an interesting problem. I've seen a lot of telescope magnets before but they were always small "pen size" for your shirt pocket.

My brother brought the one shown in the picture to the right home from Harbor Freight Tools in Gresham for me. Once I held it, it was just right, especially with my hands being about sixty percent numb which made the handle perfect for me.



NetworkofCare.Org

Usually when we discover a resource it's listed in the "FYI" section of the MSSP newsletter. However, every once in a while we hit gold. Networkofcare.org. is an internet resource that's a jackpot full of rubies and pearls! Because some folks are shy about navigating the information highway, please join me on a "virtual visit" to the networkofcare.org

Sitting at your computer get on the Internet, type in networkofcare.org, click Sr. & People with Disabilities, click Oregon, click Multnomah. At the top of your computer screen you should see 6 primary sections: Service Directory, Library, Assistive Devices, Links, Legislature & My Folder. To the left of your screen you will see another bank of important resources. Make a note to yourself to visit these sites later, they are chalked full of useful information.

Most of the issues we deal with (at MSSP) are covered under sections Service Directory and Assistive Devices so we'll spend our time there. Go to Service Directory, click on Adult Care (Residential) and up pops 49 different homes. Here's what the screen looks like:

ABC Comfort Residential Care

Phone Number: (503) 555-0606

Address: 123 SW Anywhere St. Portland, OR 97219

Administrator: Sam Q. Public

Licensed since: 2003

Licensed capacity: 10 beds

Owner: Sam Q. Public

Operator: Sam Q. Public

More = a map, driving directions and public transportation options.

To return to the other 9 separate categories within this subcategory simply use the blue arrow located at the top left hand corner of your screen until you get to Service Directory.

Now let's pretend we want to know about wheelchair dresses. We start by going to Assistive Devices, click Aids for Daily Living, click Women's Clothing, click Wheelchair Dress. Here's what appears on your screen!

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NetworkofCare.Org continued

Assistive Devices

Products >> Aids for Daily Living >> Women's Clothing >> Wheelchair Dress

Products are listed alphabetically.

1. BACK CUTAWAY DUSTER (MODEL A1120)

The Back Cutaway Duster, model A1120, is a women's dress designed to allow for greater air circulation. It features a cutaway back and is ideal for women with incontinence. Made of a cotton/polyester blend, it is available in assorted prints. SIZES: ...[\[More Information\]](#)

2. BACK SNAP/ZIP FRONT DAY DRESS (MODEL 124) & BACK SNAP/ZIP FRONT DAY DRESS (MODEL 123)

The Back Snap/Zip Front Day Dress, models 123 and 124, come in polyester and cotton/polyester blend fabrics, with two full pockets, self belt, and center kick pleats. SIZES: Small, Medium, Large, and Extra to Extra Extra Extra Large. COLOR: Assorted ...[\[More Information\]](#)

3. CUT OUT SEAT DUSTER

Women's duster with back snap closure, cut out seat. Two patch pockets, matching collar, short sleeves. Poly/cotton. Sizes: S,M,L,XL,2X....[\[More Information\]](#)

4. PLEATED DRESSES (MODEL 145 & 146)

The Pleated Dresses, models 145 and 146, are designed for use by wheelchair users. Both models feature two extra pleats under the front pockets for extra fullness, a front zipper. Model 145 is made of cotton/ polyester. Model 146 is made of polyester...[\[More Information\]](#)

5. SEATLESS BACK SNAP DRESS

Women's dress with cut out seat for wheelchair users. Back closure with snaps, cuffed short sleeves, rounded collar front and back. 1 patch pocket. Poly/cotton blend. Sizes: S,M,L,XL....[\[More Information\]](#)

Now wasn't that educational and fun? Well you are now on your own.

Keeping Cool



As the outside mercury soars don't forget to keep your body temperature cool. So do your errands in the morning. Research shows heat contributes to MS exacerbations. Take a few moments to read these simple tips to keep this summer safe:

INSIDE

THERMAL DRAPES/CURTAINS- are an inexpensive way to save energy dollars during the summer and winter! They can be found at department stores like Linen & Things, Bed, Bath & Beyond, JC Penney and thru home catalogs like BrylandHome.

FANS/SWAMP COOLERS/AIR CONDITIONERS – Tower circulating fans now come with remote controls! MSSP clients say these are the best (fans) out there. Swamp coolers are alright except most need the ice changed regularly. If you rely on a portable window air conditioner make sure you get the right size unit (BTU) for the room. For example, a 5000 BTU will cool an 8X10 bedroom space but does very little to cool a 12X16 living room.

OUTSIDE

CLOTHING – Mom's advice still stands – cover your head - wear a hat. Commercially you can purchase all kinds of items ranging from cooling wrist bands to vests. In a pinch you can freeze wash cloths and water bottles for short trips. Put the frozen cloths on the back (or front) of your neck. The frozen water bottles are great to drink as they thaw and to put against your head, etc.

Here are some sites that sell cooling vests and other products:

Cool Tek
info@heatrelief.com

OccuNomix International Inc.
www.occunomix.com

Air Gas Direct – 1 800 827-2338

Don't forget about MSSP's Summer Comfort program – see Page 10 and 11 for details.

Confronting Clutter Reprinted with permission from the MS Association of King County!

How to Declutter Your Life by Gregg Robinson

The Phenomenon of Clutter

We are a materialistic society, encouraged at all ages and at every turn to be consumers and accumulators of possessions. Americans, it seems, have a “thing for things.”

Almost unknown before 1970, the storage unit business has grown from 1,500 to 2,400 square feet in the same time.



Some people can maintain order with all of these additional things in this additional space, but for many others, it is a serious problem.

Clutter has become such a big issue that there are now enough professional organizers and “declutters” to form their own trade group (The National Organization of Professional Organizers). The wish to get better organized and “downsize” one’s home has led to the publication of many books and articles on the subject, as well.

Cluttering, and the more serious problem behavior known as hoarding, are often issues with the elderly, but can affect anyone. For people who grew up in the Great Depression, there are real historical antecedents to their tendency to save things, and their great reluctance to throw things away. For others, though, clutter is more of a psychological issue.

The Psychology of Clutter

Smith College psychologist Randy Frost, PhD, has studied and written on the phenomenon of “compulsive hoarding.” His studies indicate that hoarding behavior exists across the income spectrum; it is related to materialism, but is not just a Western experience. It may have a cultural component, and tends to run in families.

Compulsive hoarding has been linked to OCD (Obsessive-Compulsive Disorder) and ADHD (Attention Deficit-Hyperactivity Disorder). Because it runs in families, it may have a genetic component. There is no link to childhood poverty, as originally thought, but there is a link to childhood emotional deprivation and the level of warmth expressed in the family during

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Confronting Clutter (Continued)

adolescence. Frost estimated that there are as many as 4 million hoarders nationwide, but many more individuals who fall somewhere else in the spectrum of problematic cluttering behavior.

The National Study Group on Chronic Disorganization has developed a 5-Point Clutter Scale. Homes at Level One are characterized by clutter that is “not excessive”. Levels Two and Three have “increasing blockage of hallways and exits, certain room not fully usable, etc.” Levels four and five require professional intervention. Cluttered people (CPs) are creative, tend to have lots of interests; they may be teachers or have craft hobbies, and unrealistic numbers of projects in process.

Clutter and the “MS Brain”

MS cognitive problems may include deficits in:

Short and/or long term memory

Concentration

Complex problem solving

Conceptual reasoning

Decision-making

Planning

Fatigue is also a huge problem. Each of these can make sorting and organizing difficult and can lead to excessive clutter, or can make the tasks of organizing seem overwhelming.

Why Reduce Clutter?

Living in a cluttered home can worsen depression, reduce motivation and productivity, and can be physically dangerous as well (danger of tripping and falling, exiting quickly in an emergency, etc.) especially for someone with mobility or balance problems. Clutter tends to worsen and to feel more overwhelming the longer it is not addressed, often working in tandem with depression to form a “vicious circle.”

Getting organized can help you think more clearly, find things more easily, plan your days more effectively, and have more time and energy for other things (this may be especially important for people living with MS).



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Confronting Clutter (Continued)

How to Help Others Sort and Reduce Clutter

Much of the sorting process involves deciding what to throw or give away. The hardest items to throw out (especially for the elderly) may not be related to fond memories but to untapped potential “artifacts of unused life” (i.e., projects never completed, books not read, trips not taken, etc.) The process is very much a life-review and grieving process. For people who are unable to tackle the problem alone and must ask for help, there may be denial or shame involved.

Helpers may need to do a lot of listening, and would do well to plan on this and leave ample time for it. An impatient, well-organized helper might have difficulty with this part of the job. When getting started, “prime” the person who needs the help – ask them what their most ridiculous area of clutter is, or what area of category bothers them the most, and start your work there. It is important to pay attention to mood; if someone is angry, for example, it may be therapeutic to begin with something like throwing away old letters. Another suggestion is to start with the bathroom, where most people start their day. Even something as simple as a clean, washed sink and mirror gives someone a psychological boost when this is the first thing they see in the morning.

Work out a specific plan with the CP for getting organized, with step-by-step, attainable goals. Involve other friends and family members – give them attainable goals to help the CP. Other tips: take photos of old items or record reminiscences, and make a “memory box”. Donate items and thereby support a favorite charity or organization, or give items away to specific, identified friends or family members.

NOW YOU CAN WIN TOO!

Nellie Karsseboom of Woodburn proudly smiles as she displays \$50 in Fred Meyer gift certificates she won just for signing up to receive our newsletter on-line during the June 14 annual MSSP picnic!!!

You, too, can become a winner. Sign up today to get the fall issue on-line (even if you’ve contacted us by email before). Simply send an email with your name, street address, telephone number and email address to: candycehayes@msoregon ATTENTION: FALL NEWSLETTER: by August 15, 2008 to be eligible to win a \$60 gift certificate **AND** your choice of a Tri-Met LIFT 20-Ride **OR** Regular Tri-Met Monthly bus pass **OR** \$40 gasoline gift certificates!!! That’s \$100 in winnings! The winner will be announced at the MSSP Christmas Party!



Summer 2008

We want to introduce you to MSSP's air conditioner program "Summer Comfort." Through this life-saving/enriching program, the MSSP with help from private donors* gives new portable air conditioners, with remotes, to individuals diagnosed with MS living in the state of Oregon and SW Washington. If you have MS then you know first-hand heat can actually cause your body to "short circuit" and throw you into an exacerbation (MS attack). For our community air conditioning is no luxury – it's a necessity!



Application procedures are below. Simply complete the form on the backside and return it to us by no later than 8/15/08. We ask for a \$15 donation to help offset delivery expenses. The total cost to purchase and deliver a unit averages \$175. New, portable, room window air conditioners are awarded on a first-come, first-serve basis as funds permit. MSSP strives to serve as many patients as possible. For this reason we are unable to accommodate special needs ie (freestanding or vertical) units. The machines we offer work best in windows that open (up and down) versus sliding (left to right). Some folks with sliding windows have accepted the units and inserted a piece of plexy glass or other material to close the space above the air conditioner. Once all your paperwork is received you are then placed on a waiting list. When your machine is sent (via UPS) you become the owner. As such you are responsible for the installation, maintenance and submitting all warranty information.

If you want to relieve the suffering of an MS client please send a tax deductible gift today. Every gift matters \$5, \$20, \$175, whatever amount you can afford is needed and appreciated!* To make a gift by check or money order use the enclosed envelope. If you prefer to make a donation by credit card go to firstgiving.com then type in my name (Candyce Hayes) under friend's name. My fundraising page appears which describes MSSP's "Summer Comfort" program. Donating is fast and simple. One last step, share the page with other e-friends that might be interested in supporting our worthy cause.

*100% OF THE MONEY YOU GIVE WILL BE USED TO BUY AIR CONDITIONERS....

Client Application Instructions:

1. Complete and mail Summer Comfort Application by no later than 8/15/2008
2. Include documentation of your MS diagnosis. This can be either a medical chart note that includes your name and diagnosis, SSI/SSDI verification or the card board cover off your Avonex, Betaseron, Rebif or Copaxone medication

Ways to get materials to us:

MULTIPLE SCLEROSIS SOCIETY OF PORTLAND, OREGON, INC. (MSSP)

◆Fax- 503-297-6264

◆2901 SE 122nd Ave. Portland, OR 97236

◆Email- candycehayes@msoregon.org


Candyce Hayes
Executive Director

<p>Multiple Sclerosis Society of Portland, OR, Inc. 2901 SE 122nd Ave. Portland, OR 97236 Phone: 503-297-9544 Fax: 503-297-6264 Email: candycehayes@msoregon.org</p>	<p>MSSP Office USE ONLY</p> <p>Date Received: _____</p> <p>Drs Note: _____</p> <p>Date Sent: _____</p>
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MSSP 2008 "Summer Comfort" Application - Deadline: 08/15/08

Full Name: _____

Address: _____
Street City State Zip

Telephone: _____

Email: _____

1. Do you currently receive our newsletter?

Yes [] No []

If No, check here to be added to our mailing list? []

Please select delivery method:

US MAIL [] PDF by Email []

2. When and where were you diagnosed with MS? _____

3. How did you hear about this program?

- [] Newsletter [] Website
- [] Telephone Book [] Support Group
- [] TV/Radio News Program [] Word of Mouth
- [] Your Doctor's Office [] Other : _____

4. Comments: _____

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:

- | | |
|--|--|
| <input type="checkbox"/> Membership Dues (\$20.00) | <input type="checkbox"/> Social Programs |
| <input type="checkbox"/> "Summer Comfort" | <input type="checkbox"/> Medical Equipment |

My Name: _____

Address: _____

City/State/Zip: _____

Email: _____

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:

2901 SE 122nd Ave. Portland, OR 97236

Time Dated Material

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