

# MULTA SPES

MUCH HOPE

Improving the Quality of Life for Those with MS since 1949

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## Augmentative/Alternative Communication & Assistive Technology:

### An Overview for People Living with Multiple Sclerosis and Communication Disorders

By Shana Tognazzini, MA CCC-SLP

Although it is known that severe communication disorders aren't incredibly common for those living with Multiple Sclerosis, for individuals who do happen to be experiencing communication barriers, life can feel shattered into many different pieces.

The act of communication is personalized for each one of us. The words we say, the letters we write, the phone calls we make, and even the text messages we send are all important acts of communication. But there is so much more to communication that makes up who we are as people.

Communication is the essence of our human lives. It is the manner of how we present ourselves to the world, and the method of how we express who we are as individuals. Only when we experience personal impairments do we even notice how crucial communication is to remaining an active member in our relationships, families, communities, and society.

Severe communication disorders can affect an individual's speech, safety, and functional communication. Maintaining relationships, communicating with

loved ones, and making decisions with health care providers are all elements of communication that can be interrupted due to a communication disorder. Should a person find any type of communication difficult, it may be the right time to ask their doctor or neurologist for a referral to see an Augmentative/Alternative Communication (AAC) specialist.

That's where I come in. My name is Shana and I am a Speech Language Pathologist here in the Portland area and I am also an AAC specialist. Every day I work with people in our community who are living with significant communication disorders. Together, we navigate through a world of AAC and Assistive Technology in order to find the right strategies, equipment, resources, or technology that help them meet their own personalized communication goals.

Many people ask me to define AAC. I think of Augmentative/Alternative Communication as any method or system of communication that is using a system to communicate other than normal speech. Examples of this are all around us in daily life.

Imagine a person who is unable to hear. They might communicate using sign language, writing notes and emails, and maybe even have access to specialized phone equipment like TTY devices. These are all beneficial to that person communicating, and they are all AAC systems.

AAC is often paired with other helpful Assistive Technology devices or equipment. Assistive Technology simply refers to any tools or devices that can be used to help a person do something that they want to do. Assistive Technology does not have to include high tech options, although sometimes that might be a helpful

*Continued on Page 3*

### Inside This Issue

Augmentative/Alternative Communication & Assistive Technology	1, 3 4
Director's Notes	2
Laughter Workshop Review	5
Tips For Staying Cool	5
Ways To Support MSSP	6
Mark These Dates	7

## Director's Notes by Candyce Hayes



I'm sitting here thinking what topic to cover in my notes. Then it hit me. I'll share a little trick I use when life becomes overwhelming.

I go into my home office, close the door, turn off the lights and sit down at my computer. I visit the Hubble Telescope Gallery <http://hubblesite.org/> I sit in the quiet, clicking on the beautiful and amazing pictures of the universe (as we know it today) and my mind escapes to another place. The chatter and stress melt away as I'm reminded there is so much more out

there and my vision is limited. So next time you're having a bad day try my little trick. Drop me a line and let me know if it helps you.



Visit <http://hubblesite.org/> for some stunning images

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

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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](mailto:candycehayes@msoregon.org) or call 503.297.9544.

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approach to consider. Examples of Assistive Technology can be located all around us, such as small white boards and markers, alternative computer mouse styles, personal speech amplifiers, silverware with large handles, or even wireless doorbells or speakers. Even basic tools like duct tape can be very helpful for making these items work for personalized patient needs.

Together, we can work together to channel our inner “MacGyver” in order to find creative ways to help us make certain parts of life more accessible.

When I see someone for an AAC evaluation, I like to cover several areas of communication. These major areas include speech and voice, written/electronic communication, telephone communication, and personal safety devices. However, the most important part of my evaluation is always starting with personal conversations with patients about their observations and experiences. Through our discussion we can identify personal needs, establish goals, discuss technology comfort levels, as well as identify any access needs in daily life. Once we identify personal goals, it is then our job to work together in order to match those needs with recommended AAC and Assistive Technology strategies, resources, and equipment. Sometimes therapy may include training patients and/or their caregivers in learning how to use these new tools so that patients are able to begin

benefitting from these tools right away.

If a person’s speech is so impaired that it is too difficult for others to understand, one of the AAC options that we might pursue could be a Speech Generative Device (SGD). A SGD comes in a variety of designs but essentially they are computerized devices that can be programmed to speak messages that a person types or selects. Some devices can be purchased or rented through insurance, and others require private purchase. Although the process of requesting a SGD through insurance can be involved, I always assist with completing the appropriate paperwork for financing, as well as coordinating with vendors, should patients wish to move forward with the process. After their new SGD arrives, I also work together with patients on training them in the process of using and programming the device, so that they can begin using their devices for communication successfully.

The ability to write and communicate electronically is becoming even more crucial in modern society. Important written or electronic communication access can include anything from signing written forms to logging in to an online message box after a doctor visit. It is crucial that individuals have access to these important resources. Considerations made during an AAC evaluation might include using speech-to-text software, trialing an alternative

mouse and keyboard, or creating a signature stamp in order to sign important documents easily. Even tablets and smartphones can be helpful for some people who need an easy way to type with only minimal finger movements.

If accessing the telephone has become challenging, there are different programs that we can review in order to find a solution that might work for you. For example, in most states there are free programs available to all residents that provides adaptive telephone equipment who have impairments of hearing, vision, speech, cognition, or mobility. Typically there will be an accessible telephone style that can help most patients independently access and use the phone, and together we can identify which one might be the best fit.

Personal safety device access is a very important topic that I like to address with patients for several reasons. Having access to the right system can help an active person stay independent or engaged in their community. Sometimes, even the fact that someone has access to a personal safety device can help relieve the anxiety that their loved ones might feel about safety and communication. Other people might find that having a system encourages them to continue going out and living life with the confidence of knowing help is a button push away. Naturally, this is a sensitive and personal topic, but I encourage patients to consider

*Continued on Page 4*

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having an open conversation about their needs and then we go from there.

Although AAC and assistive technology may have a reputation of being technologically involved, the reality is that it can help us interact within our world no matter which style of communication we might prefer. I find that even the most challenging issues can be addressed through education, strategies, devices, and training - and of course, a little duct tape to put everything back together.

**Are you a caregiver who is concerned about the communication needs of a loved one living with Multiple Sclerosis?**

**Listen for changes in communication.** A change in speech or voice could be an initial symptom that family members might notice first. Symptoms may include “slurry” or unclear speech, a tongue that seems or feels thick, or a softer than normal voice. Whatever the symptom or feeling, it is important to listen and communicate with each other regarding these changes. An honest conversation could help identify speech changes early, which is crucial for expanding options and intervention choices for people living with communication changes.

**Watch for changes in activities.** Have you noticed your loved one complaining of changes in their

ability to participate in their favorite activities or hobbies? Changes in access, such as not being able to type as easily or not being able to hold a phone to your ear, are often able to be addressed through the use of assistive technology. There are many tools and strategies designed to help people with mobility issues continue to do the things they enjoy and maintain their quality of life.

**Reach out for support.** Once changes have been discussed, it might be helpful to assist your loved one with reaching out to communicate about their needs. Caregivers might be relied on in order to notify the healthcare team when additional support might be necessary, especially if their loved one is experiencing changes in their communication abilities. This may also include reaching out to receive support regarding your own needs as someone’s caregiver.



Shana is a Speech Language Pathologist and AAC Specialist who works with people living with significant communication needs in the Portland Metro area. She currently serves patients at Providence St. Vincent’s Medical Center, Providence Portland Medical Center, and the Providence ALS Clinic.

For more information, you may contact her directly at 503.215.0969 or [Shana.Tognazzini@providence.org](mailto:Shana.Tognazzini@providence.org)



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## Laughter Workshop Review by Mark Woodlief

### Laughter Workshop a Roaring Success

The MSSP's debut Laughter Workshop in April was well-attended and wonderful. The afternoon kicked off with Certified Laughter Yoga Leader Laura Lou. Affirming that laughter is exercise, that breathing and laughter are connected and reinforcing the mind-body-soul connection, Laura helped Laughter Workshop participants stretch the muscles that generate laughter and produce joy. What a delight to join with others in chuckling, chortling, snickering, snorting, guffawing, and expressing glee so freely and safely together!



After Laura Lou expanded our funny muscles and awareness, Gail Hand, humorist and author of *"The Power of Laughter: Seven Secrets to Living and Laughing in a Stressful World,"* treated us to her wry wit and personal anecdotes. Thanks to Gail, every Laughter Workshop participant went home with a clown nose to help keep the glee and laughter flowing.

### Tips For Staying Cool by Candyce Hayes



Do your errands in the morning. Use thermal drapes. If you don't have central air or an air conditioner unit try using a circulating (tower) fan. Wear a hat. Get a cooling wrist band and/or vest. The Multiple Sclerosis Association of America (MSAA) has a program to distribute cooling vests to people in need. To learn more call 800.532.7667 or visit their website at <http://www.msassociation.org/programs/cooling/>

The following companies make cooling items: Glacier Tek, <http://www.coolvest.com/> Phone 800.482.0533, Polar Products, <http://www.polarproducts.com/>; Phone 800.763.8423, Coolture, <http://www.coolture.net/>; Phone 716.281.0080 and Stacool, <http://www.stacoolvest.com/>; Phone 866.782.2665. Try freezing a washcloth for short outings. Put the frozen washcloth on the back (or front) of your neck. Last thing, misting fans are helpful and can be picked up at most pharmacies.

# WAYS TO SUPPORT MSSP

## 9th Annual MJN “Help Fight MS” Slingball Tournament - ... - Book your travel now!

The Neu Brothers need your help in the fight against Multiple Sclerosis. This year we will have spectacular prizes, silent auction, new Sling gear and of course the betting board, all for a great cause! For more details



about the **9th Annual “Help Fight MS” Slingball Tournament** visit [Slingball.com](http://Slingball.com) We are also in deperate need of volunteers, not only for the weekend of the event, but starting now. How can you help? In many ways from helping coordinate the silent auction, to inventory, to day-of-event task such as: scorekeepers, set-up/ breakdown, and many other tasks. Sign up to volunteer at [Slingball.com](http://Slingball.com)

Dear all Slingball Participants, Supporters, Volunteers, Donors and then some... Thank you!!! The Neu Brothers, Randy & Carter, want to share a sincere THANK YOU for everyone who participated and/or supported the 8th Annual MJN “Help Fight MS” Slingball Tourney. We raised just

over \$15,000 to help the fight against MS! This is a new record. Candyce from the MSSP added “Your support and funds help folks with MS with products and services not covered by insurance. For example, the hot weather really makes it difficult for folks with MS and we will be able to purchase 60 air conditioners to help those who otherwise couldn’t afford them. Thank you!”



Our mother, Marilyn J. Neu, would be proud of all of you as she believed in “paying it forward” and helping others. Your dedication and participation helps make it all happen!

### 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](mailto: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		RSVP required 503.297.9544
MSSP Annual Picnic Oaks Park 7805 SE Oaks Park Way Portland, OR 97202	6/20/2015	RSVP required 503.297.9544
9th Annual MJN Slingball Tournament Pacific City, OR (Oregon Beach)	June 26th-28th, 2015	Register to donate, play or volunteer by going to <a href="http://www.slingball.com">www.slingball.com</a>
Check out our website for updated programs at <a href="http://www.msoregon.org">www.msoregon.org</a>		

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. Volunteers are available to pick up the donations

## ANNUAL PICNIC

<b>Date:</b>	6/20/2015 - <b>MARK DATE!</b>
<b>Location:</b>	Oaks Park 7805 SE Oaks Park Way Portland, OR 97202
<b>Time:</b>	11:30-1:30pm (lunch served from 12:00-1:00)
<b>Cost:</b>	<b>FREE</b> "Donations Appreciated"
<b>Limit each party:</b>	4 per family
<b>RSVP Deadline:</b>	6/15/2015
<b>Call or Email:</b>	503.297.9544 <a href="mailto:events@msoregon.org">events@msoregon.org</a>



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- Summer Comfort
- Caregiver Classes
- Social Programs
- Medical Equipment
- Greatest Need

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