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Categories are listed in alphabetical order. All listings are provided for information purposes only. No recommendations or endorsements are implied.

Remember that many resources offer services that span categories and, as such, are listed multiple times. There is a "Notes" section included at the bottom of most pages to record your own resources. Feel free to contact fellow MSVP members, friends, or family for their personal experiences with any of the resources listed as many of us have utilized these resources.

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Therapies and "Living with MS" (cont.)

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Financial Services (also see Legal / Insurance Services)

- o **AGED, Inc.....888-277-1826**
www.trusted.org
Advocates & Guardians for the Elderly and Disabled - AGED, Inc. - is a non-profit trust company that assists seniors and disabled individuals qualify for government benefits, reduce medication costs, and preserve assets. Disability Trusts / d(4)(A) Trusts, Pooled Trusts / d(4)(C) Trusts, Third Party Trusts

- o **BenefitsCheckUp**
www.benefitscheckup.org
BenefitsCheckUp is a free service of the National Council on Aging, a nonprofit service and advocacy organization in Washington, DC. Many adults over 55 need help paying for prescription drugs, health care, utilities, and other basic needs. There are over 2,000 federal, state and private benefits programs available to help but people often don't know these programs even exist or how they can apply. This site can help.

- o **Florida Department of Elder Affairs.....Lake, Marion, and Sumter counties - 800-262-2243**
<http://elderaffairs.state.fl.us/>
Provides a number of services to seniors and disabled. Find more information on their website or by calling the Elder Helpline for your county. (Lake, Marion, and Sumter all have the same phone #.)

- o **Multiple Sclerosis Foundation (MSF).....888-MS-FOCUS (888-673-6287)**
<http://www.msfocus.org/Brighter-Tomorrow-Grant.aspx>
The MSF offers The Brighter Tomorrow grant of up to \$1000 per recipient. The goal of the grant is to provide individuals with MS with goods or services to improve their quality of life by enhancing safety, self-sufficiency, comfort, or well-being. For more information and an application, visit the website. The application can be completed online, or printed and mailed to the MSF. Or call the number to have an application mailed to you. Applications are accepted from June 1 to September 1 of each year.

- o **National Council On Aging www.ncoa.org**
Offers a website, www.benefitscheckup.org, that helps locate benefit programs that can help pay for medications, healthcare, food, utilities and more.

Notes

Therapies and "Living with MS" (cont.)

- o **National Multiple Sclerosis Society – Mid Florida Chapter (NMSS)**.....800-344-4867
<http://www.nationalmssociety.org/chapters/flc/we-can-help/financial-assistance/index.aspx>
NMSS - Mid Florida Chapter offers limited financial assistance for a wide variety of needs (therapy, counseling, home modifications, etc.) to those who have been diagnosed with MS and meet the criteria for assistance. For more information and an application, visit the website.
- o **New Horizons Fund**.....888-788-9216
<http://newhorizonloanprogram.org/>
Assistive Technology & Home Based Business Loans For Floridians with Disabilities. The New Horizon Fund offers loans for the purchase of assistive technology up to \$30,000. They also offer home-based business loans up to \$20,000. The loans have reasonable rates and terms. The New Horizon Fund is a program of the Florida Alliance for Assistive Services and Technology.
- o **NORD (National Organization for Rare Disorders)**.....202-588-5700
www.rarediseases.org or 1-800-999-6673 (voicemail only)
Offers patient assistance programs to help with medication costs, insurance premiums, patient co-pay fees, diagnostic testing expenses, and appointment based travel expenses not covered by a patient's insurance plan.
- o **Senior Services**.....see page 26
See the "Senior Services" section for information on additional FL state sponsored financial aid programs.

Healthcare Products/Mobility Aids

There are numerous local stores and suppliers, online retailers, and public and private organizations that offer all kinds of healthcare products that can make life a little easier. Listed are just a few of what is available. It is not intended to be an exhaustive list. While you may prefer to shop in local stores remember that there are a myriad of online retailers that offer just about anything you can think of. There are also local and national organizations that can help with these needs.

***** Scooters, power wheelchairs, and vehicle lifts are listed under "Mobility Equipment." *****

Online

- o **Active Rollator**
Available through Amazon and other online retailers www.active-walker.com/
- o www.activeforever.com
- o **Amazon**

Notes

Therapies and "Living with MS" (cont.)

www.amazon.com

Free standard shipping on orders over \$25.00

o **Cane covers**

www.caneexpressions.com, www.kickin-canes.com , www.strutyourstuffmobility.com

o **Canes** – There are MANY online suppliers. A few are listed here.

www.fashionablecanes.com, www.walking-canes.net, www.houseofcanes.com

o www.chillypads.com

o www.cwimedical.com

o www.drleonards.com

o www.dynamic-living.com

o www.elderlux.com
www.justwalkers.com

o **Polar Products**.....**800-597-0618**

www.polar-products.com

Personal cooling gear and apparel – including neck wraps and ties, wrist wraps, vests, therapy pads, and more.

o **The Wright Stuff**.....**877-750-0376**

www.thewright-stuff.com, www.CareGiverProducts.com, www.mobility-aids.com

This retailer offers a huge variety of affordable, specialized "health care products that make life a little easier." Product categories: "In the Kitchen", "Getting Ready", "Around the House", "On the Move", "For Your Comfort." Access their website or order the catalog by calling the number above.

Organizations

The national MS organizations - and some local organizations – either have lending closets or offer programs that can provide no charge cooling equipment and/or specialized healthcare products.

o **Love, INC**.....**352-245-8774**

www.loveincheartofflorida.org

Notes

Therapies and "Living with MS" (cont.)

Summerfield location. Offers a lending closet through their medical ministry.

- o **Multiple Sclerosis Society of America (MSAA)** www.msassociation.org
Offers two important programs – the Equipment Distribution Program and the Cooling Equipment Distribution Program. The equipment program provides a varied inventory of equipment at no charge. Available items can include tub/shower chairs, grab bars, wide grip utensils, leg lifts, canes, walkers, and wheelchairs. The cooling programs offers icepack pocket cooling vests at no charge. To apply for these programs, visit their website for an application.

- o **Multiple Sclerosis Foundation (MSF)** www.msfocus.org
The MSF offers the Assistive Technology Program that may provide an AT product, help locate a product or help with funding for a wide range of devices including: aids for daily living, communication devices, computers and computer aids, environmental control systems, architectural and vehicle modifications, orthotics, seating, positioning and mobility devices, aids for vision and hearing, and cooling aids. The MSF Cooling Program can provide cooling items free of charge to qualified applicants. Items include: cooling vests, neckties, bandanas, baseball hats, and wristbands. Visit their website for more information and an application. The program cycle begins each year on February 1st and continues through June 1st. Applications can be submitted online or via postal mail.

- o **National Multiple Sclerosis Society – Mid Florida Chapter (NMSS)**.....1-800-344-4867
<http://www.nationalmssociety.org/chapters/flc/we-can-help/financial-assistance/financial-assistancedetails/index.aspx>
The Mid Florida Chapter of the NMSS offers limited financial assistance for those diagnosed with MS and who meet the criteria for assistance. If approved, the grant can provide for such items as: small durable medical equipment, glasses/vision related equipment, air conditioners, cooling vests and other cooling equipment, other assistive technology, and personal care medical supplies. Visit the website for more information, an application, and a complete breakdown of what the financial assistance program can cover. You can also call the number above to speak to a resource specialist.

- o **VHA (Villages Homeowners Association)**.....352-751-1192
www.thevha.net
Has a "Helping Hands" project that loans durable medical equipment to Villages residents at no cost. (They also accept donations.) Contact - Bill Dyer .

Home Health Care – companies

- o **Better at Home (Ocala)**.....866-409-7700 or 352-694-8100
www.betterathome.net

Notes

Therapies and "Living with MS" (cont.)

- o **Comfort Keepers.....(toll free number) 855-592-0013**
www.comfortkeepers.com
Provides non-medical personal care services and home companion services. All staff are employees of the agency and are bonded and insured. Comfort Keepers does extensive criminal background checks and drug screening on employees. Accepts private pay, VA, and long-term care insurance. Services breakdown:
 - Personal care – minimum 4 hour day @ \$21.00/hour (\$84 min); services include: bathing, toileting, transferring, dressing, feeding.
 - Companion services – minimum 4 hour day @ \$17.75/hour (\$71.00 min); services include: light housekeeping, transportation, meal preparation, laundry.
 - Bath visits - \$40.00 – 2 min. per week or \$50.00 – 1 per week Assist with bath, dressing/grooming, clean bathroom, change sheets.

- o **CSI Caregiver Services, Inc (Summerfield).....352-245-4473 or 800-282-6409**
www.csicaregiver.com
Provides full array of services. Accepts long term care insurance, the medical waiver program (a lowincome county program), and self-pay. Does not accept Medicare. All staff have undergone strenuous background checks. Services breakdown:
 - Respite care (will do as little as one hour) with two levels of service
 - a. CNA @ \$16.95/hr
 - b. Companion care @ \$15/hr
 - Shower/bath care (1 hour visit) @ flat fee of \$29.95
 - Safety assessment @\$75/hr
 - Nursing staff relief

- o **Kindred at Home352-787-2780**
www.kindredhealthcare.com

- o **Greystone Home Healthcare (The Villages).....352-205-8514**
<http://www.greystonehcm.com/HomeCare.aspx>
Skilled nursing, physical, occupational, and speech therapy, medical social worker, IV therapy, wound care, diabetic teaching, medication education, disease process teaching, new rapid recovery facility.

- o **Helping Hands Home Care, Inc. (Ocala).....352-502-4902**
Medicare skilled nursing services. Prescription required. No private pay patients.

- o **Right at Home (Tavares, serves all areas).....352-835-0101**
<http://www.rahfl.com>

Notes

Therapies and "Living with MS" (cont.)

- o **Home Instead Senior Care (Ocala).....352-366-4241**
<http://www.homeinsteadocala.com>
Call to arrange assessment. Will provide discount if using the NMSS Mid Florida financial assistance program. (see Financial Services category)

- o **Senior Home Companions.....352-874-7870**
<http://www.seniorhomecompanions.com/the-villages-fl-companionship-in-home-care.htm>
For all your companionship and in-home care service needs, contact Senior Home Companions, Inc.SM serving The Villages, FL and surroundings areas of Lake, Marion, Sumter counties and Leesburg, Ocala, and Wildwood, FL. Currently celebrating our 10th year of service, we specialize in helping people in need of assistance with daily living activities due to injury, illness, aging needs, dementia and Alzheimer's. Every care provider is personally interviewed and an extensive Level 2 background check encompassing local and FBI services is performed. Our caregivers are 50 years of age and older and provide compassionate, trustworthy, honest caring services.

Homebound Services

Meals

- o **Operation Homebound.....352-753-8484**
Operated by North Lake Presbyterian Church. Volunteers deliver nutritious meals Monday through Friday between 10:30 and 11:00 AM. Eligible participants must be home to receive the meal and have no other resource for meal preparation. Fee - \$3/day.

Home Modifications

- o **Advanced Vehicle Modification.....352-237-4146**
www.avmmobility.com
Ocala location. Offers home modifications include ramps, stair and pool lifts. Newsletter available. Owner, Paul McGuckin

- o **amramp.....407-376-7116 (c) or 800-649-5215**
www.amramp.com
Provides solutions to accessibility needs, including: residential entry ramps, portable ramps, portable roll in showers, vertical and inclined lifts, overhead patient lifts, pool lifts, and other assistive devices. Contact Missy Campbell at 407-376-7116(c) or missy.campbell@amramp.com

Notes

Therapies and "Living with MS" (cont.)

- o **MobilityWorks**.....**352-237-4146** [C](#)
Ocala location. Offers home mobility solutions. Home, porch and pool lifts give wheelchair access to and in the home. Elevator lifts, stair lifts, and ramps are a few of the products available.
- o **Multiple Sclerosis Foundation (MSF)****helpline 1-800-673-6287**
www.msfocus.org/Assistive-Technology-Program.aspx
The MSF offers the Assistive Technology Program that can help with funding for a wide range of services including architectural modifications. Visit their website for more information.

Hospice

Hospice is appropriate for a person with a life-threatening illness. Medicare and private insurance pay. Hospices listed below are non-profit agencies that will provide services for free if the patient is not covered by Medicare or private insurance.

There are two service levels:

- Full service level for when the patient's life expectancy is six months or less. Nurse visits one to three times a week. Doctor visits once a month. CNA visits one to three times a week. Plus - volunteers, social workers, chaplain, and other supportive assistance. Also provides equipment (e.g. hospital bed, walker, portable potty chairs); crisis care with 24 hour nursing for short-term crisis. Care is team-centered, with the patient fully participating in deciding the frequency of visits. Hospice House is available for end-of-the-road care. Patients may be renewed for program eligibility at six month intervals. Can provide up to five days of **respite care** if the caregiver is not available. The focus of Hospice is on symptom control and pain management.
- Pathways is a program of less intensive services when the patient's life expectancy is 12 months or less, but the diagnosis is a terminal illness. This is non-billable service, meaning no cost is involved. Nurse and social worker visit one to two times a month with 24-hour on-call service available.

**Note: Medicare cannot be billed for service from more than one treatment provider per illness. If a person has more than one disease diagnosis, hospice can bill Medicare for one disease (ie. cancer), and home health can bill for the other (ie. MS.)

- o **Cornerstone Hospice**.....**352-742-6788**
Serving Sumter and Lake County residents.
- o **Hospice of Marion County**.....**352-873-7400**

Legal / Insurance Services (incl. SSDI, long term care)

Notes

Therapies and "Living with MS" (cont.)

- o **Allsup**.....**800-649-5215**
www.allsup.com
Non-legal representation for SSDI and Medicare benefit claims. 98% success rate.
- o **Family Network on Disabilities of Florida – National Pooled Trust****727-523-8687**
www.fndfl.org Provides assistance to disabled persons to establish a special needs trust. Fees apply.
Contact Richard La Belle, Executive Director.
- o **Hill and Ponton, PA**.....**1-888-477-2363**
www.hillandponton.com
Provides legal assistance with Social Security Disability Benefits claims. Five regional offices including offices in Orlando and Deland.
- o **Catherine Linn, Atty**.....**352-391-1000**
Elder Law Specialty and Medicaid planning
- o **Rhonda D. Steller, Medicaid Planning & Resource Center Law Firm**.....**352-323-6133**
- o **Medicare Advantage Info Center**.....**407-497-3346** e-mail: ruthsantman@yahoo.com
Help with Medicare Advantage and supplemental insurance plans, Medicare qualifications, prescription drug help. Ruth is a member of an MS support group in Orlando (the Orange ANTS.)
- o **Mary Trotter, Atty**.....**352-205-7245**
Elder Law Specialty

Mobility Equipment and Vehicle Modifications

There are many things to take into consideration before getting mobility equipment or modifying a vehicle. Below are websites and online articles that can offer helpful information.

Research Resources

- o **AbleData** offers an extensive list of online publications (in PDF format) regarding assistive technology including fact sheets and informed consumer guides. Topics include power wheelchairs and scooters among many others. <http://www.abledata.com/abledata.cfm?pageid=89079&ksectionid=160164>

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Therapies and "Living with MS" (cont.)

- o **National Mobility Equipment Dealers Association (NMEDA)** offers a variety of information on what to buy and how to buy. There are postings in many different categories. www.nmeda.com/
- o **National Multiple Sclerosis Society (NMSS)** provides accessibility articles on their website. Buying an adapted vehicle – <http://www.nationalmssociety.org/living-with-multiple-sclerosis/mobility-and-accessibility/buying-an-adapted-vehicle/index.aspx>

Finding the Right Stair Lift, Ramp, and Wheelchair – <http://www.nationalmssociety.org/living-with-multiple-sclerosis/mobility-and-accessibility/finding-the-right-stair-lift-ramp-and-wheelchair/index.aspx>

Affording stair lifts, ramps, and wheelchairs - <http://www.nationalmssociety.org/living-with-multiplesclerosis/mobility-and-accessibility/affording-stair-lifts-ramps-and-wheelchairs/index.aspx>
- o **United Spinal** offers USA TechGuide, an online guide to wheelchairs, mobility scooters, and assistive technology choices. You can search for all types of assistive equipment and read (and submit) wheelchair reviews, mobility scooter reviews, wheelchair cushion reviews, and standing device reviews. www.usatechguide.org
- o **United Spinal** also offers an article (in PDF format) entitled "Canes To Wheelchairs: Mobility Alternatives". How you get around has a big impact on what you can do and where you can go. This publication, written by master clinician and educator Jean Minkel, MA, PT, is a guide that assists people in making the right choice in their selection of a mobility device. (There are two local - to NY- advertisements at the beginning of the article.) Printed booklet also available from the website. http://www.unitedspinal.org/pdf/canes_to_wheelchairs.pdf

Local Suppliers

- o **Advanced Vehicle Modification.....352-237-4146**
www.avmmobility.com
Ocala location. Accessible vans and trucks, van conversions, turning and lifting automobile seats, hand driving controls, high tech driving systems, wheelchair lifts, scooter hoists, scooters, complex wheelchairs. Home modifications include ramps, stair and pool lifts. Owner, Paul McGuckin
- o **Mobility Freedom.....352-237-4146**
www.mobilityfreedom.com
This company has six locations including Clermont, Ocala, and Orlando. Offers Offers wheelchair accessible vehicles, personal vehicle lifts, home mobility solutions, vehicle modifications, driving aids, and equipment

Notes

Therapies and "Living with MS" (cont.)

- o **Ritter Medical Equipment**.....**352-288-2646, (Lake) 352-728-2211**
www.rittermedicalstore.com
Summerfield location. Specializing in mobility products including power wheelchairs, scooters, and lift chairs. Also carry portable and modular ramps, and lifts for scooters or wheelchairs. Provides in home service.
- o **Watkins & Riggs Mobility Center**.....**352-873-4411**
Ocala location. Offers complete line of power chairs, scooters, walkers, auto lifts, seat lifts, lift chairs, ramps, and manual wheelchairs. Free mobility evaluation, free in home demonstration. Sales, service, rentals, consignments, and repairs. Accepts private insurances, VA, workers comp, and self pay.

Online

There are many online retailers that offer scooters, mobility equipment, and accessories. See the Healthcare Products section for additional listings.

- o **Active Forever** www.activeforever.com/s-12-mobility-aids.aspx
- o **CWI Medical** www.cwimedical.com/Products/home-care-caregiver/wheelchairs-walkers-canes
- o **Solar Mobility** www.solarmobilityllc.com
Solar canopy that increases mobility, visibility, and safety for users of powered wheelchairs and scooters.

Organizations

Some of the national MS organizations - and some local organizations – either have lending closets or offer programs that provide no charge mobility equipment. Check with them directly for current availability. Lending closets often provide only temporary loans.

- o **Love, INC**.....**352-245-8774**
www.loveincheartofflorida.org
Summerfield location. Offers a lending closet through their medical ministry. (Also accepts donations of used equipment.)
- o **Multiple Sclerosis Foundation (MSF)**.....**helpline 1-800-673-6287**
www.msfocus.org/Assistive-Technology-Program.aspx

Notes

Therapies and "Living with MS" (cont.)

The MSF offers the Assistive Technology Program that may provide, help locate, or help with funding for mobility devices and vehicle modifications. To apply for this program, visit their website for an application.

- o **Multiple Sclerosis Society of America (MSAA)** www.msassociation.org/programs/equipment/
Offers an Equipment Distribution Program that provides a varied inventory of equipment at no charge. Available items can include canes, walkers, and wheelchairs. To apply for this program, visit their website for an application.

- o **National Multiple Sclerosis Society – Mid Florida Chapter (NMSS)**.....1-800-344-4867
<http://www.nationalmssociety.org/chapters/flc/we-can-help/financial-assistance/financial-assistancedetails/index.aspx>
The Mid Florida Chapter of the NMSS offers limited financial assistance for those diagnosed with MS and who meet the criteria for assistance. Visit the website for more information, an application, and a complete breakdown of what the financial assistance program can cover. Or you can call the number above to speak to a resource specialist. The Mid-Florida Chapter also works with a local supplier to loan equipment from a lending closet. (Fee applies.)

- o **VHA (Villages Homeowners Association)**.....352-751-1192
www.thevha.net
Has a "Helping Hands" project that loans durable medical equipment to residents at no cost. (They also accept donations.) Contact Bill Dyer

MS Organizations and Online Resources

There are many MS organizations and all offer a wide variety of programs. Most have a web presence. We have listed the three major organizations as well as a multitude of other informative websites. In addition, there are sites started by celebrities or other well known people that can be found with a simple Google search. Try searching for David Landers, Annette Funicello, Clay Atkins, Alan Osmond, David Osmond, Nancy Davis, Montel Williams, and Teri Garr, among others. Add "and MS" to their names in your search. And it's not just celebrities who have web presences. There are many online stories, blogs, and websites that chronicle the journeys of less famous people living with MS. Try typing "MS personal stories" into your search engine.

- o **Multiple Sclerosis Society of America (MSAA)**.....helpline 1-800-532-7667
www.msassociation.org
The MSAA is a national nonprofit organization whose mission is to enrich the quality of life for everyone affected by MS. The organization provides ongoing support and direct services to these individuals with MS and the people close to them. The MSAA also serves to promote greater understanding of the needs and challenges of those who face physical obstacles.
 - Clinical Trial Information.
 - Consultations, support groups, networking, and social events.

Notes

Therapies and "Living with MS" (cont.)

- Education publications, MSi educational videos and webcasts.
- Equipment Distribution program and Cooling Equipment Distribution program.
- Free lending library.
- MRI Diagnostic Fund, insurance advocacy, and financial assistance through the MSAA MRI Institute.
- *My MS Manager* – MSAA's new mobile phone application – available for iPhone, iPad or iPod touch.
- Quarterly magazine – MS Motivator. Go to the website to read online or order print copies.
- S.E.A.R.C.H. Toolkit.
- Information available in Spanish.

o **Multiple Sclerosis Foundation (MSF).....helpline 1-800-673-6287**
www.msfocus.org

The mission of the Multiple Sclerosis Foundation is to provide comprehensive support services and educational programs to those persons affected by MS. Services that help them maintain their health, safety, self-sufficiency, and personal well-being to ensure the best quality of life.

o annual Cruise For A Cause.

- Assistive Technology program
- Complementary & Alternative Medicine (CAM) program.
- Computer Grant program.
- Home Care Grant program.
- Informative, reader-friendly print and online publications. They offer more than 110 booklets and fact sheets, including many available in Spanish.
- Lending Library.
- Quarterly print magazine – MS Focus. Free subscriptions available to MS patients. Subscribe online or call toll free number above.
- MSFYi – a concise Internet newsletter that presents the latest developments in MS research, alternative approaches to traditional treatment, prescription drug treatment, and tips for dealing with the daily challenges of this chronic illness.
- National toll-free helpline and internet helpline staffed with MSF caseworkers ready to assist.
- Peer Counseling.
- Support Group program.

National Multiple Sclerosis Society – Mid Florida Chapter (NMSS).....1-800-344-4867 <http://www.nationalmssociety.org/chapters/FLC/index.aspx> The National MS Society's vision is: A World Free of MS.

The Society's mission is: We mobilize people and resources to drive research for a cure and to address the challenges of everyone affected by MS.

The NMSS offers an extensive variety of programs, services and resources for people living with MS, including family members, caregivers and other members of their support systems. These resources can be accessed in person at chapters, online, by phone, and by mail.

Notes

Therapies and "Living with MS" (cont.)

Founded in 1958, the National Multiple Sclerosis Society's Mid Florida Chapter is committed to providing quality programs and services to an estimated 70,000 people in Mid Florida affected by MS, including family members, friends, caregivers, and employers. Serving 23 counties in Florida, the Chapter also raises money to fund cutting edge research into the cause and cure of multiple sclerosis.

- Knowledge is Power (for the newly diagnosed).
- MS Next Step (for the newly diagnosed).

-
- Client publications – more than 60 booklets and brochures.
 - Comprehensive information (online and publications) on:
 - Healthy living
 - Relationships
 - Employment
 - Insurance and money matters
 - Getting the care you need
 - Veterans with MS
 - Connection programs – support groups (like the M.S.V.P.), peer-to-peer support, and online communities (www.nationalmssociety.org/online-community/ms-connection/index.aspx).
 - Financial assistance program.
 - Keep S'myelin' – a newsletter about MS for children.
 - Local Central Florida events through the Mid Florida Chapter– Annual Meeting and Research Symposium, Day of Discovery at Seaworld, Kids Camp, Monthly teleconferences, Teen Summit.
 - Professional education – workshops and literature directed to healthcare professionals.
 - Quarterly magazine – Momentum, the flagship magazine of the National MS Society, is the largest MS-related publication in the world. Free print subscriptions available to MS patients. Call the Mid Florida chapter to subscribe. Current and past issues can be read online on the website. The Society offers a free smartphone app for Momentum. Visit the Apple App Store for the iPhone and iPad app and the Android Market for the Android app.
 - MS Activist activities. Get involved at the state or national level.
 - MS Bike.
 - MS ID card.
 - MS Learn Online – educational webcast series.
 - MS Navigator.
 - MS Walk.
 - My Life, My MS, My Decisions.
 - Scholarships.
 - Spanish resources.
 - Volunteer opportunities.

- **Accelerated Cure Project for Multiple Sclerosis** www.acceleratedcure.org

Notes

Therapies and “Living with MS” (cont.)

Accelerated Cure Project for Multiple Sclerosis is a national nonprofit organization dedicated to accelerating advances towards a cure for multiple sclerosis through its MS repository. The repository is a bank of blood samples and data from people with MS and matched controls; data that the organization makes available to MS researchers.

○ **Can Do MS**

www.mscando.org

Can Do MS, formerly The Heuga Center for Multiple Sclerosis, is an innovative provider of lifestyle empowerment programs for people with MS and their support partners. A national nonprofit organization, Can Do MS empowers people to move beyond their MS by giving them the knowledge, skills, tools and confidence to adopt healthy lifestyle behaviors, actively co-manage their disease and live their best lives.

- Lifestyle empowerment
- Nutrition and exercise strategies
- Skills training: communication, stress management, goal-setting, prioritization

○ **Center for Medicare Advocacy**

www.medicareadvocacy.org/InfoByTopic/ChronicConditions/MS.Main.htm

The Center for Medicare Advocacy is a non-profit, non-partisan organization that provides education, advocacy and legal assistance to help elders and people with disabilities obtain Medicare and necessary healthcare. They have put together an “Introduction to Medicare for People with Multiple Sclerosis” that covers both general and specific concerns.

○ **Clinical Trials website** www.clinicaltrials.gov

ClinicalTrials.gov is a registry and results database of federally and privately supported clinical trials conducted in the United States and around the world. ClinicalTrials.gov gives you information about a trial's purpose, who may participate, locations, and phone numbers for more details. This information should be used in conjunction with advice from health care professionals.

○ **Consortium of Multiple Sclerosis Centers (CMSC)** www.ms-care.org

The CMSC's mission is to stimulate and facilitate research in the field of multiple sclerosis, to develop vehicles to share information and knowledge among CMSC members and the healthcare community for the benefit of those affected by MS, and to develop and implement mechanisms to influence healthcare delivery. Offers “Essential Elements – My Personal Journey” – a self directed e-learning experience. www.ms-patientcare.org

○ **MayoClinic.com – Multiple Sclerosis** www.mayoclinic.org/multiple-sclerosis

MayoClinic.com was created to empower people to manage their health. There are four separate tabs – Basics, In-Depth, Multimedia, Expert Answers .

Notes

Therapies and "Living with MS" (cont.)

- **University of Florida (Shands), ufhealth.org**, is a comprehensive clinic for all medical needs. 1-3352-733-0111. Now has a MS Specialty Care Clinic.
- **MedlinePlus – Multiple Sclerosis** <http://vsearch.nlm.nih.gov/vivisimo/cgi-bin/querymeta?v%3Aproject=medlineplus&query=multiple+sclerosis+&x=20&y=16>
Medline Plus is the National Institutes of Health's web site for patients and their families and friends. The MS section of MedlinePlus includes an extensive collection of resources that are sectioned into six main categories.
- **MS Connection**
www.msconnection.org
An online support community of the National MS Society. Find, store and share meaningful updates, posts, videos, articles and other content about the topics you care about most. Connect with people, groups and discussions that relate to the topics that shape your world. Join conversations with others who share your experiences, challenges, and interests, and put the best resources available to work for you, so you can move life forward in the way that feels right.
- **MSFriends.....toll free hotline 1-866-673-7436**
www.msfriends.org
MSFriends has a primary mission: to improve the quality of life for people with MS, for their family and friends. MSFriends offers the first 24/7 telephone helpline staffed with people who have MS – "Friends Helping Friends."
- **MS News and Views** www.msviewsandnews.org
A website and organization created to help add education information for the global MS community via the internet and via live seminars. A place where information and knowledge are exchanged for the benefit of all persons affected by MS. This includes the MS patient, the caregiver(s), friends and the medical providers.
- **MS World**
www.msworld.org
Provides support and information about living with multiple sclerosis. MSWorld offers chat, message boards, a resource center, an arcade, a Creative Center... along with social networking connection on Facebook and most importantly, a community of people who share day-to-day challenges living with MS. Sign up for weekly e-mail newsletter on the website.
- **Multiple Sclerosis International Federation (MSIF)** www.msif.org/en/
Multiple Sclerosis International Federation (MSIF) was established in 1967 as an international body linking the activities of national MS societies around the world. The mission of the MSIF is to lead the global MS movement to improve the quality of life of people affected by MS and to support better understanding and treatment of MS by facilitating international cooperation between MS societies, the

Notes

Therapies and "Living with MS" (cont.)

international research community and other stakeholders. Goals accomplished through: international research; development of new and existing societies; exchange of information; and advocacy.

Myelin Repair Foundation

www.myelinrepair.org

Myelin Repair is a non-profit research organization that is exclusively focused on developing the next generation of MS treatments that will restore myelin.

o **National Institute of Neurological Disorders and Stroke**

http://www.ninds.nih.gov/disorders/multiple_sclerosis/multiple_sclerosis.htm

The mission of the National Institute of Neurological Disorders and Stroke is to reduce the burden of neurological disease - a burden borne by every age group, by every segment of society, by people all over the world. The site has a Multiple Sclerosis Information Page

o **National Organization for Rare Disorders** www.rarediseases.org

The National Organization for Rare Disorders (NORD) is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.

o **Neurology Now**

<http://journals.lww.com/neurologynow/pages/default.aspx>

Neurology Now is the award winning bi-monthly patient magazine of the American Academy of Neurology. It is available online or in print. Print subscriptions are available free of charge to individuals with a neurological disorder, their caregivers, and family members/friends residing in the U.S only. Go to the website to subscribe. There is an iPad app available through the Apple App Store. There are also podcasts available through iTunes. The links for the podcasts are available on the website.

o **The Myelin Project** www.myelin.org

The Myelin Project aims to accelerate research on myelin repair. The Myelin Project created a framework in which researchers can cooperate effectively by giving scientists adequate, prompt financing and by continuously interacting with them. The funds are put toward clinically oriented experiments on the cutting edge of remyelination research.

o **TurnFirst Foundation** www.turnfirst.org

When you're diagnosed with Multiple Sclerosis, this is the place to start. The goal of the TurnFirst Foundation is to provide support to help the newly diagnosed and their families be better prepared to

Notes

Therapies and "Living with MS" (cont.)

take on the physical and emotional challenges of MS, advocate for themselves, and set a course to lead fulfilling and productive lives.

o **United Spinal Association** www.unitedspinal.org

United Spinal Association is a national organization advocating for people with spinal cord injuries and disorders - including 5000 members with MS. Issues include health care, home and community services, and medical equipment access. They produce an online magazine called Action online (<http://www.unitedspinal.org/publications/action/>). United Spinal is the sponsor of the annual Independence Expo in Orlando.

United States Department of Veterans Affairs - Multiple Sclerosis Center of Excellence
www.va.gov/MS/index.asp

The Center of Excellence is dedicated to further our understanding of the disease, its impact on Veterans, and effective treatments to help manage MS symptoms.

o **WebMD**

www.webmd.com/multiple-sclerosis

WebMD provides MS health information, tools and support, including

- MS news and information
- Active MS community
- MS-specific tips and health check tool
- Weekly MS related newsletter

Pharmaceutical Company MS Support Programs

The pharmaceutical companies that make the MS disease modifying drugs as well as the symptom management drugs and devices offer extensive patient support programs. The patient programs can include web sites, financial and insurance assistance programs, support nurses – telephone, internet, and in-person, teleconferences, live educational events, online and print publications and newsletters, webinars, online support communities, and more.

Most of these patient programs are available to everyone – you do not have to be on their drug to go to a live event, call the support lines, or use their patient services. Register with the individual support program to be kept up to date about upcoming events. In addition, local MS support groups (like the MSVP) oftentimes announce these events to their membership.

Program descriptions from the DMT pharmaceutical company websites

o **Avonex support program – MS ActiveSource** www.msactivesource.com

Biogen Idec, the maker of Avonex, sponsors MS ActiveSource.

Notes

Therapies and “Living with MS” (cont.)

MS ActiveSource is a resource dedicated to helping people with multiple sclerosis live better lives. Whenever you need to find information about MS symptoms, diagnosis, or treatment, you can find it here. You'll find lifestyle tips and tools, too. Get help staying healthy with MS diet and exercise. And MS support and community will connect you to others with experience living well with multiple sclerosis.

- Free MS exercise DVDs – including “My MS Yoga”, and “Fitness with Katrina”. □ One-on-one peer mentors.
- Personal logbook.
- Monthly e-newsletter.
- Teleconferences.
- Live local MS Active Source education events.
➔ *MS Active Source live MS education events are available to all interested persons. You do not need to be taking Avonex to attend.*

o **Betaseron support program – BETAPLUS**

<http://www.betaseron.com/betaplus>

Bayer Healthcare Pharmaceuticals, Inc., the maker of Betaseron, sponsors BETAPLUS.

Living with multiple sclerosis is a challenge. No one knows that better than your BETAPLUS patient support team. BETAPLUS today combines personal support with assistive technology and online tools to help make living with MS more manageable.

- My BETA Nurse and me.
- Informative video series – “Look who's talking about MS”.
- myBETAapp – mobile app to track injections.
- "BETASERON Because" checklist.
- Affording BETASERON.
- See how to inject.
- Stay organized with *My Personal Journal*.
- Get injection reminder e-mails.
- Live local MS education programs.
➔ *BETAPLUS live MS education events are available to all interested persons. You do not need to be taking Betaseron to attend.*

o **Copaxone support program – Shared Solutions** www.sharedsolutions.com

Teva Neuroscience, the maker of Copaxone, sponsors Shared Solutions.

Shared Solutions has a patient assistance financial program and a live hotline staffed with MS trained nurses. There are also free patient educational brochures available at your neurologist's office.

- Free in-home sessions with injection training nurses.
- *Making Strides: Perspectives on Living with MS* – a free print publication supported by an educational grant from Teva Neuroscience is available in your neurologist's office.
- *MS Perspectives* – a publication supported by an educational grant from Teva Neuroscience. To receive a free subscription in print or online, visit www.MSperspectives.com.
- Live local MS education programs.

Notes

Therapies and "Living with MS" (cont.)

→ *Shared Solutions live MS education events are available to all interested persons. You do not need to be taking Copaxone to attend.*

o **EXTAVIA support program – EXTAVIA Go Program**

www.extavia.com/info/PatientSupport/Patient-support-program.jsp Novartis, the maker of EXTAVIA, sponsors the EXTAVIA Go Program.

- *Go Program Navigators* are available seven days a week.
- Personalized injection training.
- Help with the reimbursement process for EXTAVIA.

*****EXTAVIA support program is available only to EXTAVIA patients.

o **Gilenya support program – Gilenya Go Program** www.gilenya.com/info/support/ms-support.jsp

Novartis, the maker of Gilenya, sponsors the Gilenya Go Program.

Once you have been prescribed GILENYA, you'll have access to:

□ A Navigator and a GILENYA Nurse.

- Benefits information and co-pay assistance.
- MS information, news and updates, tools, and help getting started with your GILENYA treatment □ Live local MS education events.

→ *Gilenya Go Program live MS educational events are available to all interested persons. You do not need to be taking Gilenya to attend.*

o **Rebif support program – MS LifeLines®** www.ms lifelines.com

EMD Serono/Pfizer, Inc, the makers of Rebif, sponsor MS LifeLines®. MS LifeLines® is an extensive patient support program both for those patients taking Rebif and for the MS community. Their slogan – *[you]NIQUE SUPPORT Because your needs are different from others' needs, MS LifeLines® offers support that's customized for you.*

Call MS LifeLines® toll-free at 1-877-447-3243 anytime, day or night. A live representative is always available to take your call.

Support services offered:

- Customer support specialists – available seven days a week.
- Field nurses – available five day a week for extended hours. In the comfort of your home, a MS Lifelines can show you proper injection technique and share tips for managing side effects.
- MS LifeLines® eNewsletter.
- *MS LifeLines®* magazine is a periodic publication now offered in two convenient formats: a traditional printed magazine or an interactive, environmentally-friendly e-magazine.
- Nurse support specialists – available seven days a week. Dedicated to providing on-going training and support to people with relapsing MS.
- Peer Connection program - Talk one-on-one with an MS LifeLines® ambassador - someone living with relapsing MS.
- "*Real Talk Real Answers*" – free mobile app for iPhone available through the Apple App store.

Notes

Therapies and “Living with MS” (cont.)

- Reimbursement specialists – available six days a week. Dedicated to Affordable Access ensuring that cost is not a barrier to staying on Rebif.
- “Talk MS” – monthly web event series designed to help you live well with MS. Past “Talk MS” videos are archived online.
- Treatment Journal.
- Live local MS education events.
- Live local “CHAT” program hosted monthly by the MS LifeLines® field nurse.
 - ➔ *MS LifeLines® live MS educational events and the CHAT programs are available to all interested persons. You do not need to be taking Rebif to attend.*

o **TYSABRI support program – Biogen Idec Patient Services**

www.tysabri.com/tysbProject/tysb.portal/_baseurl/threeCollLayout/SCSRepository/en_US/tysb/home/treatment-with-tysabri/tysabri-patient-services.xml

Biogen Idec, the makers of TYSABRI sponsor Biogen Idec Patient Services.

- *ActiveAccess* for TYSABRI – your source for financial and insurance assistance.
- Teleconference Series – a convenient way to get up-to-the-minute information.
- Live local MS education programs.
 - ➔ *Live MS educational events are available to all interested persons. You do not need to be taking Tysabri to attend.*

Program descriptions from the makers of symptom management drugs and devices

o **Acthar support program – ASAP: Acthar Support and Access Program**

www.acthar.com/mspatient/ms

Questcor, the maker of Acthar, sponsors A.S.A.P.

A.S.A.P. is a free resource staffed with knowledgeable specialists who help you by providing:

- Home injection training by licensed nurses.
- Informational DVDs.
- Medication shipment tracking.
- Patient assistance and access programs.
- Reimbursement and coverage support.
- Live local education programs.
 - ➔ *Acthar live MS educational events are available to all interested persons. You do not need to be taking Acthar to attend.*

o **Ampyra support program – Ampyra Events** www.ampyra.com

Accorda, the maker of Ampyra, sponsors Ampyra Events and Patient Support Programs.

Ampyra Events provide free educational information and support on Ampyra. These programs are open to all people living with MS, their families and care partners.

- Ampyra Connect.

Notes

Therapies and "Living with MS" (cont.)

- Ampyra Patient Support Services and Co-Pay Program.
- Online webinars.
- Live local MS education programs.
 - ➔ *Ampyra live MS educational events are available to all interested persons. You do not need to be taking Ampyra to attend.*

o **Medtronic support program – Ambassador Program**

www.medtronic.com/patients/severe-spasticity/therapy/index.htm

Medtronic, the maker of the Medtronic Baclofen pump, offers an Ambassador Program. Visit the website to read the personal stories of people who chose Medtronic ITB TherapySM (Intrathecal Baclofen Therapy) to treat severe spasticity symptoms. Have a live, one-on-one conversation with an ITB Therapy Ambassador through their Ambassador Program.

o **NEUDEXTA Patient Support program**

www.nuedexta.com/patient-caregivers/patient-support.shtml

Avanir, the maker of NEUDEXTA, offers reimbursement support and financial assistance.

Prescription Programs

Most of the pharmaceutical companies offering MS disease modifying therapies or symptom management drugs offer some sort of financial assistance or programs to provide lower cost drugs. Most of these companies are listed in the "Pharmaceutical Company MS Support Program" section of this guide.

Pharmacies and grocery store pharmacies offer many generic drugs for \$4 or less (or free as in the case of antibiotics.) While this does not help for MS therapy drugs, reducing the costs of other drugs taken can be useful. You can call the stores, ask in person, or check the prices online by going to the store's website and checking the list of low cost drugs. In addition, some pharmacies have prescription saver clubs where for a small annual fee you may purchase generic drugs at lower costs.

BenefitsCheckUp

www.benefitscheckup.org/

BenefitsCheckUp is free service of the National Council on Aging, a nonprofit service and advocacy organization in Washington, DC. Many adults over 55 need help paying for prescription drugs, health care, utilities, and other basic needs. There are over 2,000 federal, state and private benefits programs available to help but people often don't know these programs even exist or how they can apply. This site can help.

- o **Disabled American Vets (DAV)** www.davrxcard.com/asp/index.asp Prescription Card

Notes

Therapies and "Living with MS" (cont.)

- o **Lake County Elder Affairs**
www.lakecountyfl.gov/departments/community_services/health_and_human_services/elder_affairs/ □
Florida Discount Drug Card
 - Medical Beneficiary Outreach and Assistance Program

- o **Medicare**
www.medicare.gov
 - Compare drug and health plans.
 - Get extra help with prescription drug costs.
 - Input list of your drugs and the site will list cost and pharmacies.
 - Medicare basics and resource locator and more.

- o **National Organization for Rare Disorders (NORD)**
www.rarediseases.org/patients-and-families/patient-assistance
Since 1987, NORD has administered Patient Assistance Programs to help patients obtain life-saving or life-sustaining medication they could not otherwise afford.

- o **Paralyzed Veterans of America (PVA)**
www.pva.org/site/c.a1lRK9NjLcJ2E/b.6433405/k.97CA/Membership_Benefits_Prescription_Card.htm
Membership open to veterans of the US Armed Services who have suffered a spinal cord disease (like MS)
Membership Benefits: Prescription Card

- o **The Partnership for Prescription Programs** www.pparx.org/
The Partnership for Prescription Assistance helps qualifying patients without prescription drug coverage get the medicines they need through the program that is right for them. Many will get their medications free or nearly free.

Resources for Members Affected By Cancer

- o **Cleaning for a Reason**
www.cleaningforareason.org
Cleaning For A Reason is a nonprofit organization partnering with maid services to offer free professional house cleanings to improve the lives of women undergoing cancer treatment.

- o **The American Cancer Society** www.cancer.org
The American Cancer Society has a variety of programs available to Villages residents. Call the 24 hour number (1-800-227-2345) for more info on the services below. (Call Hope Lodge directly.) □

Notes

Therapies and "Living with MS" (cont.)

Look Good, Feel Better – program at The Villages Regional Hospital that provides cosmetology services to women suffering from cancer.

- Man to Man Support Group – for men suffering from prostate cancer.
- Road to Recovery – transportation to medical appointments. Three business day notice requested.
- **Hope Lodge**.....**352-338-0601**
Free housing service to those required to stay in Gainesville for medical treatment. The Lodge is sponsored by Winn Dixie. Contact the Lodge directly to determine availability.

Respite Care

Respite care provides a break for those caring for another person. Usually working for a few hours per week, respite care providers cannot provide any physical services (such as feeding, bathing, or lifting), they will simply sit and visit with a person, perhaps read or play games to allow the primary caregiver time off from caregiving duties. Two local churches provide respite care regardless of whether someone is a church member.

- o **St Mark's Catholic Church**.....**Summerfield**
Contact: Mary Goedan.....352-874-1722
- o **St Timothy's Catholic Church**.....**The Villages**
www.sttimothycc.com/Ministries.htm
Contact: Mellissa Kryman352-750-4302

Senior Services

- o **BenefitsCheckUp**
www.benefitscheckup.org/
BenefitsCheckUp is free service of the National Council on Aging, a nonprofit service and advocacy organization in Washington, DC. Many adults over 55 need help paying for prescription drugs, health care, utilities, and other basic needs. There are over 2,000 federal, state and private benefits programs available to help but people often don't know these programs even exist or how they can apply. This site can help.
- o **Lake County Elder Affairs**
www.lakecountyfl.gov/departments/community_services/health_and_human_services/elder_affairs/
Lake County has an extensive senior services program. Access their website or download their Elder Affairs Services Directory organized into 52 categories.
(www.lakecountyfl.gov/pdfs/Community_Services/Elder_Affairs/Elder_Affairs_Service_Directory.pdf)

Notes

Therapies and "Living with MS" (cont.)

- o **Florida Department of Elder Affairs.....Lake, Marion, and Sumter counties - 800-262-2243**
www.elderaffairs.state.fl.us/
Florida Department of Elder Affairs is the primary state agency administering human services programs to benefit Florida's elders. It provides a number of services to seniors and disabled. Find more information on the website or by calling the Elder Helpline for your county. (Lake, Marion, and Sumter all have the same phone number)
 - Aging Resources Centers
 - Disaster Preparedness
 - Elder Helpline
 - Elder Update newsletter
 - Employment for Seniors
 - Health Insurance for Seniors
 - Public Meeting Notices
 - Report Elder Abuse
 - Senior Centers in Florida
 - Senior Legal Services

- o **Marion County Senior Alliance** www.marionsenioralliance.com
Marion County offers extensive programs through the Senior Alliance. Access the website or download the Resource Directory
(www.marionsenioralliance.com/articles/Senior%20Alliance%20Resource%20Directory%202011.pdf)
Check the website for details on monthly live informational meetings covering a variety of topics.

- o **Sumter County Elder Affairs Advisory Committee**
Download the "Sumter County - RESOURCE DIRECTORY FOR SENIORS"
sumtercountyfl.gov/DocumentView.aspx?DID=261

Support Groups

- o **MSVP – MS Support Group.....The Villages**
www.mssupportgroup.org o Support Group leaders: **Barb Gaines** -
bgaines@thevillages.net.....**352-874-9673**
Mary Grunewald – pagrune@hotmail.net.....352-391-9707
- o Monthly Lunch - 1st Tuesday of the month at one of the excellent eating establishments in and around The Villages.
- o Monthly Bowling - 2nd Tuesday each month, 10:00 AM at Spanish Springs Lanes. o Monthly Meeting - 3rd Tuesday of the month at 10:00 AM in the Ricardo Montalban Room at the La Hacienda Center. o Monthly Carepartners – 4th Tuesday of the month, 10:30 AM in the Ricardo Montalban Room at the La Hacienda Center.

Notes

Therapies and "Living with MS" (cont.)

- o **MS Support Group of Ocala, Marion County.....Ocala**
Our mission is to reach out and build bridges for a brighter tomorrow through faith, education and positive support from our members and the community. Our purpose is to share life experiences and offer mutual aid - all in a safe, confidential place; to leave each meeting with hope and renewed encouragement, and for each member to know that they are not alone.
When: Second Tuesday of the month 5:30 p.m.-7:00 p.m. (no December meeting)
Where: Marion County Public Library (Conference Room A), 2720 East Silver Springs Blvd.
Contact: **Tonya - 352-789-0663 / tonyaocala@aol.com**

- o **Pity Us Not Support Group of Central Florida.....Tavares**
www.pityusnot.webs.com/
Our MS self-help group offers support to all persons living with MS, their families and friends. We provide a place to come together to share information on research, coping skills and life's problems - a place of encouragement.
When: First Friday of the month 10:00 a.m. to 12:00 p.m.
Where: Florida Waterman Hospital - Conference Room D, 1000 Waterman Way (east of 441)
Contact: **Lita – 352-343-8110 / pityusnot@aol.com or Cherie – 352-321-2465**

- o **Mighty Survivors Support Group of
Clermont.....Clermont**
Our mission is to reach out and support others who have Multiple Sclerosis, and their loved ones, as well as to educate and to raise awareness in our community.
When: Fourth Wednesday of the month at 10:00 a.m.
Where: National Training Center (at South Lake Hospital), 1099 Citrus Tower Blvd
Contact: **Aimee - 352-242-2350 / amarkussen70@gmail.com
Peggy - 352-243-1366 / lewpeg@embarq.com**

Therapies and "Living with MS"

Aquatic therapy

Aquatic exercise and aquatic therapy are excellent ways to promote movement for those people with MS. There are a great number of benefits that exercising in the water can provide. Water provides opportunities for recreation, relaxation and exercise for people with MS at every level of ability.

Here in The Villages we are fortunate to have a great number of outdoor pools in our community. While exercise in water is extremely beneficial, MS patients need to be cautious of heat sensitivity issues. It is best to exercise in water less than 84 degrees. A small portable pool thermometer is helpful to have to test the water temperature. These are available online (www.amazon.com/Ace-Pool-Thermometer-9-12/dp/B000RXZU5K/ref=pd_sim_lg_1) and at pool supply retailers.

Notes

Therapies and "Living with MS" (cont.)

- o **Aquatic Therapy - National MS Society** www.youtube.com/watch?v=bZQUYaG0Zqc
- o **Water Walking Assistant device** www.mssupportgroup.org/water_assistant.htm
- o **You Can...Exercise in Water**
www.nationalmssociety.org/living-with-multiple-sclerosis/you-can/exercise-in-water/index.aspx
- o **You Can...Swim Like a Fish**
<http://www.nationalmssociety.org/living-with-multiple-sclerosis/you-can/swim-like-a-fish/index.aspx>
- o **Lake Centre for Rehabilitation** www.lakecentre4rehab.com
Six locations, three in The Villages. Featuring the HydroWorx1000 rehabilitation pool with underwater variable-speed treadmill;

Canine Companions

- o **Canine Companions for Independence - Orlando.....1-800-572-2275**
www.cci.org
Canine Companions for Independence is the oldest and largest non-profit organization that enhances the lives of children and adults with disabilities by providing highly trained assistance dogs and ongoing support to ensure quality partnerships. All our services are provided free of charge.
- o **My Angel with Paws - Deland.....386-490-4949**
www.MyAngelWithPaws.org
My Angel With Paws, a non-profit, volunteer based organization that rescues, breeds, raises, and trains service dogs for children and adults with physical challenges. Placement of our dogs is free of charge to our recipients.

Equine assisted therapy

- o **American Hippotherapy Association** www.americanhippotherapyassociation.org
Good source for information on hippotherapy (horseback riding therapy).
- o **Freedom Ride – Orlando.....407-293-0411**
www.freedomride.com

Notes

Therapies and "Living with MS" (cont.)

Freedom Ride is dedicated to enriching the lives and experiences of children and adults with disabilities in the Central Florida area through therapeutic horseback riding and related activities.

o **Marion Therapeutic Riding Association (MTRA) – Ocala352-732-7300**

www.mtraocala.org

Serving the Heart of Florida since 1985, Marion Therapeutic Riding Association (MTRA) is a premier accredited therapeutic horseback and carriage riding organization for individuals of all ages challenged by physical, mental or emotional disabilities. Since our inception, we've had one clear mission: to offer the miraculous benefits of therapeutic horseback riding to persons of all ages and capabilities that are physically, mentally or emotionally challenged. There is magic in horses that has been proven to be strong medicine.

o **Can Do MS**

www.mscondo.org

Can Do MS, formerly The Heuga Center for Multiple Sclerosis, is an innovative provider of lifestyle empowerment programs for people with MS and their support partners. A national nonprofit organization, Can Do MS empowers people to move beyond their MS by giving them the knowledge, skills, tools and confidence to adopt healthy lifestyle behaviors, actively co-manage their disease and live their best lives.

- Nutrition and exercise strategies

o **Multiple Sclerosis Association of America (MSAA)**

http://www.msassociation.org/programs/videos/closerlook_benefits.exercise.asp The MSAA offers an educational web video entitled "A Closer Look...The Benefits of Exercise."

o **Multiple Sclerosis Foundation (MSF)** <http://www.msfocus.org/msf-publications.aspx>

The MSF offers a fact sheet on adaptive sports and a printed booklet entitled "The Fitness Prescription." These can be ordered on the website.

o **National Multiple Sclerosis Society (NMSS)**

www.nationalmssociety.org/living-with-multiple-sclerosis/healthy-living/exercise/index.aspx

This site lists many online videos and .pdf files with more information. Printed booklets include: "Exercise as Part of Everyday Life" and "Stretching for People with MS" among many others.

o **USF Health in The Villages.....352-753-6200**

<http://villages.health.usf.edu/default.aspx> (Click on "Healthy Community" for fitness information.) There is a new health resource in The Villages – University of South Florida. (USF). USF Health has opened an office in Lake Sumter Landing. They offer local events and programs and a complete website that addresses a multitude of health questions including fitness.

Notes

Therapies and "Living with MS" (cont.)

- o **Adaptive Golf Foundation of America - Sarasota** www.agfofamerica.com

Our mission is to improve the quality of life for individuals with physical and/or cognitive disabilities by providing specialized disabled golf and life skills programs to enhance their physical, mental, social, and emotional well-being.

Therapies and "Living with MS" (cont.)

- o **The Florida Disabled Outdoors Association**
www.fdoa.org

- o **Florida State Parks** www.floridastateparks.org

Many of Florida's state parks offer accessible facilities and programs. For additional access to trails and beaches, all terrain wheelchairs are located in parks throughout the state. Accessible boat tours are available at some parks. For information about specific facilities and programs, please call or write to the park that interests you.

- o **US National Park Service**

<http://www.nps.gov/findapark/passes.htm>

<http://store.usgs.gov/pass/access.html> (FAQs about the Interagency Access Pass)

The Access Pass is free for U.S. citizen with permanent disabilities. A pass is your ticket to more than 2,000 federal recreation sites. Each pass covers entrance fees at national parks and national wildlife refuges as well as standard amenity fees at national forests and grasslands, and at lands managed by the Bureau of Land Management and Bureau of Reclamation. A pass covers entrance and standard amenity fees for a driver and all passengers in a personal vehicle at per vehicle fee areas (or up to four adults at sites that charge per person).

http://www.nps.gov/pub_aff/access/trails.htm

This site from the National Park Service lists information on national parks in five categories: accessible trails, accessible opportunities, accessible vistas, accessible camping, and accessible picnic areas.

- o **U Can Ski 2 – Winter Haven** www.ucanski2.com

A Florida based water ski club that provides adaptive water ski events for children and adults with various disabilities.

Notes

Therapies and "Living with MS" (cont.)

Massage therapy

For people with MS, massage is used to relax muscles, reduce stress and relieve conditions exacerbated by muscle tension

- o **Massage Therapy information - National MS Society** <http://www.nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/treatments/complementary--alternative-medicine/massage-and-bodywork-therapy/index.aspx>

Physical therapy (PT) and Occupational therapy (OT)

- o **National Multiple Sclerosis Society (NMSS)** <http://www.nationalmssociety.org/about-multiple-sclerosis/what-we-know-aboutms/treatments/rehabilitation/index.aspx>

Notes

Transportation

County Transit Information

- o **Lake County Connection**.....**352-742-6580**
http://www.lakecountyfl.gov/departments/community_services/public_transportation/lake_county_connection/
A state-funded program, the paratransit service, Lake County Connection, provides low-cost transportation throughout Lake County to individuals who qualify as “transportation disadvantaged” as defined by state statutes.

- o **Marion Transit Service**.....**352-620-3071**
<http://www.ocalaf1.org/tpo/TPO.aspx?id=681>
Marion Transit Services provides transportation by appointment for the transportation disadvantaged citizens of Marion County through a fleet of regular and wheelchair lift equipped vans. Marion Transit Services is a subsidiary of Marion County Senior Services, a private, non-profit social service organization

- o **Sumter County Transit****352-568-6683**
<http://sumtercountyfl.gov/index.aspx?nid=95>
Sumter County Transit offers door-to-door service and deviated shuttle routes. The Transit fleet is able to accommodate wheelchairs, children requiring a car seat, and service animals. Read more about the services in the [Passenger Guide](#) or in the [Transportation Disadvantaged Service Plan](#). The program is set up on a priority trip basis; first medical, then employment, education/training, nutrition followed by all other trips. It is recommended you make a reservation at least 3 days in advance of your appointment due to driver/vehicle availability. M-F 8-5

Accessible Travel sites

- o www.AbilityTrip.com
Provides frequently updated information on accessible travel and links to other sites.

- o www.Access-Able.com
Information and resources about: traveling with a special need, disability magazines, access guides for cities, resorts and attractions, wheelchair or scooter rentals, accessible transportation and more

- o www.EmergingHorizons.com
An online quarterly newsletter that provides news, resources, and destination information for travelers with mobility challenges.

- o www.GlobalAccessNews.com
International wheelchair accessible travel reports & resources for all disabled people.

- o **National Multiple Sclerosis Society (NMSS)**
<http://www.nationalmssociety.org/living-with-multiple-sclerosis/healthy-living/travel-andrecreation/index.aspx>
 An excellent site full of information and resources including links to “The Doctor’s Travel Tips,” “Barrier-Free Travel: A Nuts and Bolts Guide for Wheelers and Slow Walkers,” and “Accessible Nature Trails,” among many others.

- o **www.sath.org**
 SATH, the Society for Accessible Travel and Hospitality, provides news, fact sheets and destination access guides.

- o **Venture Magazine** www.venturetrav.com
Venture magazine is a free magazine devoted to accessible travel, filled with interesting people, exciting destinations, and articles providing “behind the scenes” glimpses into how world-renowned companies such as Walt Disney World, Royal Caribbean International, and Holland America Line are addressing—and achieving—accessibility for their guests with physical disabilities. Visit the site to read the magazine online or subscribe for a free subscription via mail.

Air Travel

- o **TSA.....toll-free helpline..855-787-2227**
 The TSA has a toll-free helpline for travelers with disabilities called TSA Cares. The agency advises calling 72 hours before traveling so it can coordinate support with a customer service agent at the airport’s security checkpoint, if needed.

Check out the TSA web page – Travelers with Disabilities and Medical Conditions – for helpful information about screening procedures, medications, service animals, and more.
<http://www.tsa.gov/traveler-information/travelers-disabilities-and-medical-conditions>

- o **United Spinal Association**
 United Spinal Association has produced a booklet entitled “Accessible Air Travel, A Guide for People with Disabilities”. You can read it for free online in a .pdf format at http://www.unitedspinal.org/pdf/accessible_air_travel.pdf or order a printed copy from their website for \$2.95
<http://www.unitedspinal.org/disability-publications-resources/disability-publications/>

Cruising

Cruising is one of the easiest and most comfortable ways for a disabled person to travel. Virtually everything that a cruise line offers is available to disabled passengers. From the Momentum travel article...”Any ship that docks in a US port has to follow ADA regulations but passengers will need to confirm accessibility for shore excursions. Ask your travel agent or contact the cruise line to verify that those on

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your trip provide roll on access. See www.CruiseCritic.com for reviews of specific cruises, or the websites of individual cruise lines for more information, destinations, and prices.”

The individual cruise lines’ websites also offer accessibility information. And the cruise terminals, especially in Port Canaveral, do a great job of helping you get to your ship. Some lines are listed below with links to their accessibility pages. Please note that river cruises and sailing ships tend to be far less accessible than ocean cruises.

- o **Carnival** http://www.carnival.com/cms/fun/cruise_control/EMB_guest_specials_requirements.aspx
- o **Celebrity Cruises**
http://www.celebritycruises.com/explore/ships/detail.do?shipCode=RF&tab=accessibility%2Fexplore%2Fships%2Faccessibility.do%3Fpagename%3Dship_accessibility_RF%26shipCode%3DRF
- o **Holland America Line**
<http://www.hollandamerica.com/cruise-vacation-planning/PlanningAndAdvice.action?tabName=Shipboard+Life&contentMenu=Accessible+Cruising>
- o **Norwegian Cruise Line**
<http://www2.ncl.com/about/accessible-cruising>
- o **Princess Cruises**
http://www.princess.com/news/backgrounders_and_fact_sheets/factsheet/Princess-Access-MakesCruise-Vacations-Accessible-For-Passengers-With-Disabilities.html#.UD2rnaN62So
- o **Royal Caribbean International**
<http://www.royalcaribbean.com/allaboutcruising/accessibleseas/home.do>
- o **MScruisers.com** www.msruisers.com
Cruises designed for MS patients, family members and friends who share an interest in the MS community. Travel with fellow MSers who believe that health and fitness are powerful tools for overall well-being and independence. These cruises are especially suited for those who want to travel and interact with others who are facing the same challenges and are aiming for the same goal of enjoying life to its fullest as they go through the process of adjusting their lifestyle to best suit their constantly changing needs.
- o **Multiple Sclerosis Foundation (MSF)** <http://www.msfocus.org/Cruise-for-a-Cause.aspx>
The MSF hosts an annual MS cruise. The MSF Cruise for a Cause provides an empowering adventure traveling with fellow MS cruisers, their families, as well as healthcare professionals, and MSF staff. On days at sea, the MSF Cruise for a Cause offers a variety of onboard workshops and discussion groups on vital topics of particular interest to people with MS. Leading MS neurologists and other healthcare professionals present the latest information on MS research and treatments, and offer practical advice and solutions to help you live with MS. The trip is an unforgettable experience.

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- o **Equipment rentals**

Sometimes it's easier to rent a wheelchair or scooter or other equipment for a trip rather than bringing your own. If traveling on an airplane you can risk damage to your own equipment by baggage handlers. In those instances, renting equipment is the best way to go. There are national and local companies who rent equipment. The largest ones are listed below.

- o **Care Vacations.....877-478-7827**
www.carevacations.com

CareVacations is the leading provider of mobility scooters, folding wheelchairs, oxygen rentals and other special needs equipment for cruise passengers with disabilities and aging travelers. Working hand-in-hand with all major cruise lines and disability experts and partnering closely with the travel agent community, CareVacations' name is synonymous with trust, reliability and quality.

- o **Scotaround.....888-441-7575**
www.scotaround.com

Scotaround assists thousands of customers each year in all types of travel, from conventions and cruises to popular vacation destinations like Orlando and Las Vegas and across the USA. So whether you call it a scooter, ECV, PMV or an electric convenience vehicle, Scotaround can provide you with an electric mobility vehicle, powerchair or wheelchair for your rental needs or for purchase.

- o **Special Needs At Sea.....800-513-4515**

www.specialneedsatsea.com Special Needs at Sea is the leading global provider of wheelchair rentals, scooter rentals, oxygen rentals and other special needs equipment rentals. Recommended by the world's major cruise lines for superior service and value, Special Needs Group also services guests visiting hotels, resorts, theme parks and convention centers.

Theme Parks

Here in Central Florida we have a wealth of theme parks to enjoy. Most of the large parks and many of the smaller and/or regional parks do an excellent job of accommodating their physically challenged guests and helping them enjoy a great experience. Contact the website before a trip to the park or call the park for information on accessibility features. Listed below are some of the majors.

- o **Busch Gardens Tampa**

<http://seaworldparks.com/en/buschgardens-tampa/Park-Info/Know-Before-You-Go> Click on the link and scroll down to "Special Needs and Accessibility Guide" for complete information.

- o **Disney World**

<http://disneyworld.disney.go.com/guests-with-disabilities>

Overview of accommodations for guests with disabilities at both parks and resorts. Includes links to printable guides for guests with disabilities for all four Disney World parks.

- o **Seaworld Orlando**

<http://seaworldparks.com/en/seaworld-orlando/Park-Info/Accessibility-Guide>

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This guide provides an overview of services and facilities available for guests with disabilities who are visiting SeaWorld Orlando. We are committed to providing a safe and enjoyable environment to all guests.

o **Universal Orlando**

<http://www.universalorlando.com/Resort-Information/Accessibility-Information.aspx>

Accessibility information. Includes link to Universal Orlando's Rider's Guide for Rider Safety and Guests with Disabilities.

Travel Agencies Specializing in Accessible Travel

When you interview an agent (especially one that does not specialize in accessible travel), consider asking the following questions...

1. How long have you been an accessible travel agent?
2. How many clients have you had with disabilities (especially your type of disability) and what types of arrangements have you made in the past?
3. Do you have experience in arranging accessible travel in the destination I plan to go to, and have you been there?
4. Do you have contacts in the destinations that can assist me if something goes wrong?
5. Do you have relationships with the various access desks at the airlines, cruises, resorts etc. who you can call on my behalf?
6. What type of training have you had in accessible travel, the needs of those with disabilities, etc.?
7. May I speak with some of your past clients who can provide a reference?

o www.abletotravel.org.....**888-211-3635**

Able to Travel, a program of United Spinal Association is a full service accredited travel agency that understands the needs of wheelchair users and all individuals with disabilities. They can assist you with booking: airlines, hotels, ground transportation, accessible car service/taxis, cruise packages, trains, resort packages, travel insurance, tour groups, mobility to medical equipment rentals, lift equipped van/car rentals with hand controls, and more.

o www.accessiblejourneys.com.....**800-846-4537**

At Accessible Journeys our accessible lifestyle vacations harmonize our clients' abilities with the resources needed for slow walkers and wheelchair travelers to visit the living classrooms of culture and history around the world. Our wheelchair accessible group vacations and cruises welcome families, single travelers, and their friends. As a private alternative, we also create custom accessible vacations for travelers who want their own vacation at their own pace.

o <http://wheelchairescapes.com/>..... **866-382-3596**

Wheelchair Escapes is a travel agency specializing in accessible travel created by a woman whose husband has MS.

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