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MID AMERICA CHAPTER
MS CONNECTION NEWSLETTER

MONEY MATTERS
WHAT ARE JOB ACCOMMODATIONS AND HOW DO I GET ONE?

BY KRIS GRAHAM

At the Society’s Information Resource Center, where people with multiple sclerosis and their families can call an MS Navigator® at 1-800-344-4867 for help on a range of topics, we recently received a question about how to obtain accommodations when multiple sclerosis starts to get in the way of doing your job. So here’s what I told our caller.

First, I explained what accommodations are. They can be things like new equipment or changes to existing equipment. Another type of accommodation may be a change to your work routine, such as hours worked. (Read a few real-world examples of accommodations that have worked for people with MS at www.askjan.org/soar/MS/MSex.html.)

I then pointed out two things to remember about accommodations:

01 You must be able to perform the essential functions of your job. The ADA (Americans with Disabilities Act) does not require employers to reduce essential job functions, but you can ask to change how you perform an essential job function. Usually employers decide which job functions are essential.

02 Your employer does not have to provide you with your first choice in accommodations. The employer has to provide an accommodation that is reasonable and effective, if available — so be ready to discuss alternatives.

Next, we discussed whether or not the ADA applied to the caller’s situation. People can request reasonable accommodations under the ADA if:

• They work for an ADA-covered employer;
• They are “qualified” to do the job; AND
• They are a person with a disability as defined by the ADA.

ADA-covered employers include private employers with 15 or more employees, all state and local governments, employment agencies and labor unions. If you’re not sure whether your employer is covered by the ADA, contact your regional ADA Center (look up your
LETTER FROM THE PRESIDENT

I am thrilled and humbled to be assuming the role of chapter president for the National MS Society Mid America Chapter. I have been looking forward to making my home in Kansas City and getting to know the many other communities that make up our chapter—and now, the time has arrived.

It is never easy leaving a community and job that you love but, I know the Mid America Chapter is where I belong. Through my 11-year tenure with the National MS Society, Upper Midwest Chapter in Minneapolis, I took on a variety of roles. I am confident those experiences have prepared me well for this new adventure—I cannot wait to share it with you.

We have a lot of work to do but with the great staff, volunteers, and donors in our mix, I know we will be successful. This is going to be our year. We will change the world for people affected by MS because we are stronger together.

I look forward to getting to know each one of you. Please do not hesitate to stop by the office and say ‘hello’!

Cheers to great adventures ahead,

Jenna Neher
Chapter President, National MS Society, Mid America Chapter

TAX TIME REMINDERS

Don’t forget! You can help end MS forever by donating to the National MS Society through the Multiple Sclerosis Fund on the Missouri State Income Tax Form. This tax check-off program allows taxpayers to designate a $1-$200 donation. Money contributed will be subtracted from any income tax refund owed to the individual by the state or would be added to the income tax the individual owes the state.
region at www.adata.org) or visit JAN (the Job Accommodation Network) at www.askjan.org. Both organizations are free and confidential resources. If your employer is not covered by the ADA, contact an MS Navigator at 1-800-344-4867 for assistance in exploring other possible legislation that may protect you.

“Qualified” to do the job means that someone has the “skills, experience, education, or other requirements” of the position, and “can perform the essential functions of the position with or without reasonable accommodation.” (For more information, download the Disability Law Handbook — Employment and the ADA for free at www.swdbtac.org/html/publications/dlh/employment.html.)

The ADA’s definition of a “person with a disability” now includes most people with MS, thanks to the passage of the ADA Amendments Act and updated Equal Employment Opportunity Commission regulations. Although people with MS do not necessarily have to disclose their diagnosis, they must provide enough information for the employer to understand that they are a person with a disability. For more about workplace disclosure and a helpful worksheet, visit www.nationalMSsociety.org/disclosure.

My next advice to the caller was to be prepared!

Before you request accommodations, make sure you can answer all of the following questions:

• How is MS affecting your job, potential job, or application process?
• Why are you requesting accommodations?
• What information will you need to provide to your employer (or potential employer) to clarify the impairment affecting your work and the accommodation that will remedy the situation?
• What accommodations or changes to your work will be effective?
• When should you speak with your employer (or potential employer)?
• Who should you involve in the conversation?
• How should you follow up on your request?
• What are your rights if things go wrong?

Finally, I told the caller that if she had additional questions, an MS Navigator would be standing ready for her call.

Kris Graham is the employment manager for the National MS Society.

THESE RESOURCES CAN PROVIDE MORE HELP AND INFORMATION


JAN’s Searchable Online Accommodation Resource (SOAR) at www.askjan.org/soar/index.htm.
LIVING WITH MS

2016 CHAPTER DATES TO REMEMBER

January 15 – Deadline for 2016 Scholarship Applications.

MS shouldn’t stand in the way of an education. This is why the National MS Society’s scholarship program exists — to help highly qualified students who have been diagnosed with MS or who have a parent with MS achieve their dreams of going to college. To learn full details about eligibility & the application process, please visit www.nationalMSsociety.org/scholarship or call 1-800-344-4867.

January 21 - Snowflake Social, Wichita, KS

Connection with others can be a powerful experience for those living with MS. Come connect and celebrate the New Year with families in your community at the MS Society Snowflake Social! Featuring hors d’oeuvres, tea, soda and water. Please note registration is limited to 6 per family.

Fox and Hound Restaurant, 1421 Waterfront Parkway, Wichita KS, 6-8 pm


January, 26 - Snowflake Social, Springfield

Double Tree by Hilton, 2431 N Glenstone Avenue, Springfield, MO 65803.

An evening event to include refreshments and food. More information will be available when registration opens January 6.

January 30 - SSDI Day


February 9 - Kansas MS Action Day

February 24 - Nebraska MS Action Day

Spring/Summer Everyday Matters - Omaha, Springfield, Wichita

Everyone has their own idea of their best life. For people living with multiple sclerosis, the idea of that “best life” can change due to the challenges of having a chronic, unpredictable and lifelong disease. The National MS Society’s Everyday Matters, supported by Genzyme, a Sanofi company, was an interactive national project that uncovered stories of real people facing the everyday challenges that MS can bring on the path to one’s best life.

Everyday Matters is a program that provides tools for people living with MS to live their best life. This program is divided into two meetings. The first meeting is about laying the groundwork with a discussion of findings and tenets of positive psychology- the why. During the second meeting members will take an even deeper dive into the principles themselves- the how- asking group members to share how they are or will apply the principles to live their best life with MS.

HOW TO SIGN UP

Call 1-800-344-4867 to register or view the program calendar on the chapter website, www.msmidamerica.org. Please note: registrations generally open 4-6 weeks before the event. Please review the program page at msmidamerica.org.
National MS Society and Can Do MS Webinar and Telelearning Series, 2nd Tuesday of the month, 7-8:15 p.m. CST
The 2016 Webinar & Telelearning Series brings together a collaboration of MS experts — to help you learn strategies to live your best life with MS. Each free webinar & telelearning program features two presenters with time for Q&A. To register for these programs go to http://bit.ly/nmsstelelearning

Your Mind Is a Muscle, Too: The Relationship between Exercise and Cognition, January 12, 8 p.m. CST
A benefit of exercise that you may not have considered is strengthening your mind, more specifically, your cognition. Learn how the relationship between exercise and cognition can help your MS management. Robert Motl, psychologist, and Mandy Rohrig, physical therapist, will lead an interactive investigation of how and what types of exercises can improve common cognitive challenges.

Navigating Career Change: Working with MS is Possible!, February 9, 7 p.m. CST
Working with MS is possible, but can be challenging at times. What do you do when you can no longer do your job? What do you do if working in your field is no longer an option? How do you know when it’s time to make a change? Listen to career coaches discuss steps you take to effectively navigate career transition periods. Please join Danielle Moser and Debra Heindel as they explore the challenges of working with MS. Danielle and Debra are co-authors of FOCUS: Creating a Career + Brand Clarity, which outlines a very simple, easy to follow process that helps professionals gain clarity to be able to develop an entrepreneurial approach to self-marketing.

Managing Your MS Symptoms with Technology, February 23, 7 p.m. CST
An Assistive Technology Practitioner will share how technology can assist in the management of certain MS symptoms that may become barriers to productivity. Learn about a variety of useful tools and devices to help make work more accessible. Join Mark Surabian, founder/owner of ATHelp.org and Anna Lenhart, project manager with AbleData to learn how to utilize technological solutions in the workplace.

The Complete Guide to Social Security Disability, March 15, 7 p.m. CST
Presented by Jamie Hall, Esquite and Amy Wallish, CEO CEO/Certified Benefits Counselor Full Circle Employment Services

GET CONNECTED
Remember that you are not alone! There is an entire MS community out there for you!

• Sign up to receive Society emails at: www.nationalMSsociety.org/signup.

• Join the MSConnection.org community: www.MSconnection.org.

• Talk to an MS Navigator. Ask an MS Navigator for help to navigate the challenges of MS. Find personalized answers to your unique needs, up-to-date information, referrals and practical resources. Call-1-800-344-4867, contactus@nmss.org or www.facebook.com/NavigatorMS
Like all employees, people with a progressive illness or disability can bring valuable skills, talents and abilities to the workplace. There is a wide range of supports available to help you find and keep employment, whether you are employed at the time of on-set of disability, your illness progressed, or if you are unemployed and looking for the right position to fit your abilities.

One question many employees with a progressive illness struggle with is when or if to disclose your illness to your employer. The decision of when to tell your employer about your illness, or if to disclose a disability is a very personal one. If your disability is not obvious, and you don’t feel that it will affect your job performance, many employees choose not to disclose. Other employees with a progressive illness realize that sooner or later, they will need to ask for extended time off, a modified work schedule, or other accommodations. Those employees who choose to disclose prior to needing a workplace accommodation will most likely be met with less resistance from their employer, and will often find that their employer is more compassionate towards their needs.

Disclosure of a progressive illness or disability depends on each job seeker or employee and their unique situation.

If you are disabled and need assistance looking for employment, your state Vocational Rehabilitation (VR) office is one resource you should consider. VR can match you with a service provider who can assist you in creating a resume, learning interview skills, completing job applications and assessment tests and acting as an advocate. The services they can provide depend on your individual needs. Most VR services can provide on-site job coaching support once employment is obtained. These supports consist of a job coach present at your place of employment, helping you to learn your new job and the most efficient way for you to do it. Job coaching fades as you demonstrate the ability to perform your job duties independently. Your VR counselor will determine which services best suits your needs. VR may also offer assistance with interview and job related clothing, and assistance with transportation costs if you financially qualify.
Vocational Rehabilitation may also be able to provide you with vocational training or education that you may need to transition to a new career, if your previous employment is no longer possible due to your illness or disability. Types of training could include college or university, trade school, a community rehabilitation program or on-the-job training program. They could also cover the costs for tuition/fees, as well as books and supplies.

If you already have a job, VR can help you keep that job by suggesting reasonable accommodations. Reasonable accommodations for persons with a progressive illness, according to the EEOC, include leaving for doctor's appointments and/or to seek or recuperate from treatment, taking periodic breaks, and permission to work at home. A reasonable accommodation could also include anything from adaptive equipment to reduced work hours, or even retraining for a more suitable job within your company. Another resource for workplace accommodations is the Job Accommodation Network (JAN). JAN is a consulting service that provides information about job accommodations and the employability of people with disabilities. Some of the services that are provided by JAN are one-on-one counseling about ideas for job accommodations and requesting those accommodations. JAN does not help individuals find employment, but provides helpful up-to-date information to job seekers.

Another available resource is the online U.S. federal government website, www.disability.gov. This website provides valuable information on disability programs and services throughout the nation. This website can assist you with how to apply for disability benefits and how to find a job. Also, check out the resources in your local community to help you get the supports you are looking for.

Remember, you have value and can be an asset in the workplace with the right supports and the right place of employment!

Michelle VanGordon has been working as a Job Developer since November of 2008. She is currently working for the Rehabilitation Institute of Kansas City. Michelle is certified in Employment Services Training through the College of Employment Services and has helped hundreds of individuals with disabilities achieve and maintain competitive employment.

Natural supports, which are the relationships that occur in everyday life, should be utilized whenever possible in the workplace. Work colleagues can often be a great form of emotional support. Having a support system at work can be comforting in times of stress. If you found your job through networking with someone you know who was already working for the company, that is your first natural support. Talking to this person about expectations in the workplace before starting your job can be a great help.
During the first week of November, over 900 MS Society volunteer leaders came together for the 2015 Society Leadership Conference in Ft. Worth, Texas.

Together We Are Stronger was the theme of the conference. Through workshops, general sessions, formal and informal gatherings, participants experienced firsthand that the MS Society is stronger when we all work together to end a world free of MS. Throughout the conference volunteers from across the country were recognized for their dedication in living out the mission of the MS Society.

Three people from the Mid America Chapter were among those being honored this year. Jeff Peier and Duane Haverty both received the Lifetime Achievement Award for volunteering for more than 30 years with the MS Society.

Jean Lawing received the Volunteer Hall of Fame Honor in the area of Programs and Services for her decades of service and leadership for programs benefiting persons with MS. These three individuals are shining examples of people in our chapter dedicating their time to helping those with MS live their best lives.
Erin Schatteman is a self-proclaimed ‘non-runner’ even though she recently finished a half-marathon at Walt Disney World on February 22nd, 2015.

Erin was diagnosed with MS almost 8 years ago. For almost 7 years, Erin saw minimal symptoms. “About a year ago, I relapsed. The tingling started in my feet and continued to move up my body. I couldn’t carry my kids and struggled even just to walk. I panicked when it didn’t correct itself,” she recalled. “I was showered with support by a group friends that share a common interest which is our love of Disney,” Erin said. “So, after this relapse, I decided I was going run the Disney Princess Half Marathon with these friends.”

It was not an easy road to Orlando. “The first run I went on, I only ran a mile and it took me 20 minutes,” laughed Erin. “I signed up for the half, paid my money and set a goal—I knew however hard the road, I had to do it.” “I do have most of the feeling back now but still cannot feel traction when I run. So, that caused some concern.” “Training was a great tool for me to raise awareness about MS. I think a lot of people look at me and think it would be easy for me to do this when ‘easy’ is farthest from the case. MS can be an ‘invisible disease’ and people can forget you have it.”

Erin and her friends used the Finish MS fundraising program to raise money for the MS Society through the Walt Disney World Princess Half Marathon platform. “Finish MS made me stick to my goal. I had people invested in my participation—it was really motivating. They believed in me, I had to show them I could do it.” Erin proclaimed.

She admitted the half marathon was harder than she expected. “The actual marathon was a super fun, great experience but it was really hard. I had to be ready to run at 3 AM! I had barely slept and was super busy on the days leading up to the event.” “The race was intimidating. I didn’t think I could finish but, just by chance, I ran into two of my Disney friends toward the end and they motivated me to finish.”

As for advice for others motivated to run a race after being diagnosed with MS? “Lean on others.” Erin said.

“Don’t be afraid to ask for help. Make your goal be just to finish. Don’t worry about times etc. Utilize the Finish MS platform as it allows you to easily connect with others to create a team, fundraise and update your supporters. It’s free, simple to use, and helps you set and achieve a goal.”
ADVOCACY

MS & EMPLOYMENT, AN ADVOCACY PERSPECTIVE

There is increased discussion in today’s society about maintaining appropriate work/life balance. Smart phones allow us to be constantly plugged into work communications, businesses are doing more with less, personnel and family obligations seemingly continue to mount, and more families are reliant upon dual incomes. All of this adds up to feeling as if we are barely maintaining sanity, stability and happiness both on and off the job. Adding multiple sclerosis to the equation presents additional stress and uncertainty in employment, family dynamics and decision making.

Receiving a diagnosis of MS gives reason to pause and seriously re-evaluate life’s priorities. In the short term, an assessment of the physical and mental demands of current family responsibilities and job functions should be conducted, being certain to address your immediate health needs for adequate MS disease management. The National MS Society has tools and resources to assist with this ever evolving and ongoing process. One tool that can assist with organizing your thoughts is the Self-Advocacy Worksheet.

The Self-Advocacy Worksheet is designed for you to organize your thoughts and actions for effective self-advocacy in various life settings. It can be used to conduct a personal employment assessment, helping you to decide if you can or should work. If you determine that you could work if reasonable accommodations were made, it will help you think though what form accommodations could take and even how to begin the conversation with your employer. It provides a framework for people with MS to prepare, practice, role play, rehearse, and take action.

Another good resource is the Job Accommodation Network (JAN). JAN offers an accommodation and compliance series for employers. Their MS specific publication provides employers with information about the disease, ADA information, accommodation ideas, and resources for additional information. It provides specific accommodation ideas to address most MS symptoms.

The National MS Society also has an array of work related publications.

- ADA and People with MS- What the Americans with Disability Act means in employment, public accommodations and more.
- Focus on Employment- On disclosure, ADA, fatigue and cognitive issues on the job, and telework options.
- Information for Employers- A brochure for people to give to their employers if they decide to disclose their MS.
- A Place in the Workforce- On employment strategies and options.
- Should I Work? Information for Employees- General overview of the employment issues that might concern people newly diagnosed.
• The Win-Win Approach to Reasonable Accommodations- A practical guide to obtaining the workplace accommodations described by the ADA.

Your self-advocacy and accommodation planning is made possible by the advocacy of millions of disability rights activists and organizations that worked to pass the Americans with Disabilities Act (ADA). Over the past 25 years the ADA has reduced barriers for people living with disabilities and allowed people affected by MS to live their best lives. Allowing people with MS to stay active in the workplace (if that is the chosen path) and be a productive member of society. It prohibits discrimination against people with disabilities in employment, transportation, public accommodation, communications, and governmental activities.

The success of the ADA serves as a reminder that we are stronger when we bond together to effect change that will improve the rights and opportunities afforded to people living with MS and other disabilities. That’s why the National MS Society includes advocacy as part of their work. The Society seeks to seize opportunities and build pathways with the government, communities and the private sector so people with MS get what they need. This often includes advocating for the passage of legislation that reduces barriers to employment for persons with disabilities and ensuring access to health care.

Medicaid Expansion is a way to provide people living with MS who fall into the Medicaid “gap” necessary access to health care. People with MS earning between the current Medicaid eligible income level but less than 138% of the Federal Poverty Level (less than $11,770 a year for a single person) do not qualify for insurance plans on the Federal Health Insurance Exchange. This leaves many people who are working that do not have access to employer health insurance or Medicare entirely without affordable health insurance options.

In 2016, the Mid America Chapter will continue its Medicaid Expansion advocacy in Kansas, Missouri and Nebraska.

What We Are Trying To Accomplish:
To expand Medicaid to provide quality, comprehensive healthcare for our most vulnerable populations, including many with MS.

Why It’s Important: Medicaid provides comprehensive health coverage to nearly 9 million non-elderly people with disabilities and to 10 million low-income Medicare beneficiaries who rely on Medicaid to fill Medicare’s gaps including many people living with MS. Medicaid is a true safety net for people with MS as MS is one of the most expensive chronic diseases and people with MS are often forced to stop working because of their disease.

So, should a person living with MS work? Productive work can be a part of a satisfying life and MS does not spell the end of being productive. The real question involves how, where and at what level you will work. The resources provided in this issue of the MS Connection, as well as ongoing support from a MS Navigator, may help you to make the best determination for your personal circumstances, maintaining the right work/life balance possible for you and your family.
MULTIPLE SCLEROSIS PATIENTS NEEDED!

Researchers at UMKC are investigating how MS patients make treatment choices. The study will require one 2 hour visit.

PARTICIPANT CRITERIA: To qualify, you must:

• Be diagnosed with multiple sclerosis
• Be 18 years of age or older
• Speak English as your primary language

Participants will be compensated $50 for their time.

IF INTERESTED: Call 816-235-5428 or email umkcmsmedfeedback@umkc.edu

HOME ACCESS TAX CREDIT

If you made any accessibility modifications (such as installing ramps or grab bars) to your home this year, you might also be eligible for the Home Access Tax Credit if you are a Missouri or Kansas resident. For more information: visit www.dor.mo.gov (Missouri) or http://www.ksrevenue.org/ (Kansas)