### **Young Adult Webinar Series**



### **Employment Issues** August 21, 2018

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### Young Adult Series<sup>™</sup>

www.cando-ms.org/multiple-sclerosis-programs/young-adult





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www.cando-ms.org



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### **Webinar Speakers**



Steve Nissen, M.S., CRC Director, MS Navigator Services Delivery National MS Society Washington, DC

Roz Kalb, Ph.D. Psychologist West Bath, ME



### Employment Issues & MS: What We Know

- 90% of people with MS have work experience
- Approx. 60% are working at time of diagnosis
- Within several years, ~40% remain in the workforce
- Diagnosis often occurs mid-career; many with advanced degrees/training; moving up "the career ladder"
- Importance of recognizing implications of adult-onset condition

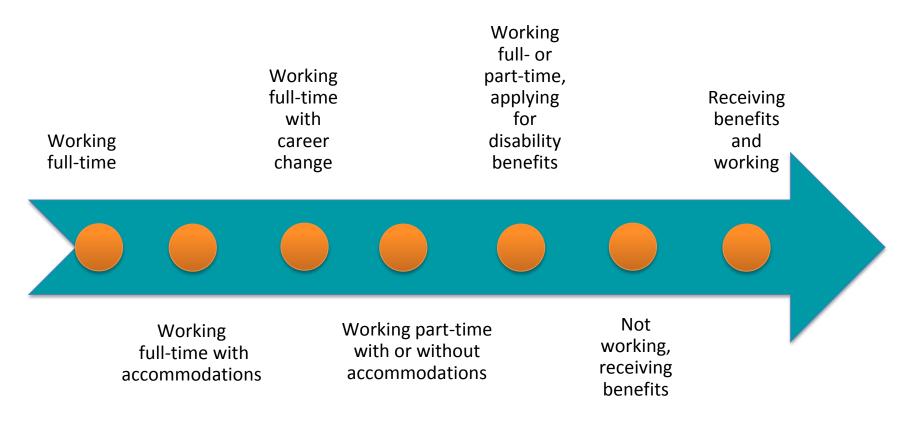


# The Role of Work in Our Lives

- Central to our personal identity
  - "I am a teacher...a nurse...homemaker... repair person"
- Source of personal growth and fulfillment
  - Self-esteem
  - Satisfaction/accomplishment
  - Intellectual stimulation
  - Enjoyment
  - Professional relationships
- Financial support for ourselves & families
- Benefits, e.g. health insurance



### **Employment & Benefits Continuum**





### **Common Legal Protections**

- Americans with Disabilities Act (ADA)
  - Disclosure; Reasonable accommodations
  - Equal opportunity; Anti-discrimination
  - Applies to conditions like MS (ADA Amendments Act of 2008)
- Family and Medical Leave Act (FMLA)
  - Job-protected leave without pay & maintenance of benefits
- Consolidated Omnibus Budget Reconciliation Act (COBRA)
  - Continuation of health insurance coverage



### To Tell Or Not To Tell: Disclosure

- Major concern for many individuals living with MS
- Personal decision to make; stressful, especially with "invisible symptoms"



- Issues most commonly arise when MS starts to interfere with work or when looking for a new job - newly diagnosed.
- May need to disclose to obtain an accommodation or short-term disability leave
  - Relate disclosure to accommodation



### To Tell Or Not To Tell: Disclosure At The Workplace

- Not always mandatory; consider the pros and cons
- Consider timing
  - Before interview? At interview? Upon offer? Once start job? Never?
- Consider type of employer
  - e.g. Sec. 503 federal contractors, Schedule A federal agencies





### Disclosure Dilemma: Advantages & Disadvantages

### **ADVANTAGES**

- Reduces stress
- Educates others about MS, adult-onset disabilities
- Allows for accommodations now or in the future
- Freer to examine health insurance and other benefits
- May simply feel more comfortable



### Disclosure Dilemma: Advantages & Disadvantages

### **DISADVANTAGES**

- Fear of rejection...ultimate fear of losing job
- Fear of being pigeon-holed at work
- Fear of being seen as different or weak by others
- Might want to maintain privacy



# **Tips on Disclosing**

- Think about it... script it... practice it
- Avoid medical terminology & complete medical history
- Use "sound bites" & easy-to-understand language
- Determine **WHO** appropriate person is...**WHEN** is the correct time...**WHAT** to say...**WHY** disclose?



# **Tips on Disclosing**

- Four general components of disclosure script
  - 1) Disclosing the condition (actual medical diagnosis or not?)
  - 2) Relating it to individual's symptoms
  - 3) Requesting appropriate accommodations
  - 4) Finishing on a positive note
- Remember: Disclosure ultimately needs to be an <u>interactive process</u> - the employee plays a major role and has bulk of responsibility



### Invisible Symptoms & Non-Apparent Disabilities

- "But you look so good" mentality
  - Prevents others from "accepting" hidden disabilities as real
- Perceptions can be stressful for employee; may be hesitant to ask for needed accommodations
- According to ADA, individuals don't need to disclose unless requesting accommodations, but may feel the stress of not telling others
  - Am I being dishonest?
- Hidden symptoms can cause just as many limitations as visible ones!



### **Accommodation Strategies**

- Technology
  - Computer, assistive, ergonomic workstation, etc.
- Arrangement of workspace by task frequency and priority
  - e.g. access to frequently visited areas of office
- Flexible work schedule
  - Telecommuting, altered hours
- Accommodation may change over time as needs/symptoms change, e.g. an exacerbation
- No two people are the same accommodations need to be looked at on case-by-case basis



### **Accommodations For Common MS Symptoms**

#### **Symptoms**

Fatigue

#### **Cognitive symptoms**

#### Accommodations

- Flexible work hours
- More frequent/longer breaks
- Rest area, rest period
- Telecommuting
- Eliminate distractions
- Calendar/day planner
  Organize work area, memory aids
  Project-focused, use written job
- instructions

Heat/temperature sensitivity

- A/C or fan
- Cooling vest
- Work from home on hot or cold days



### **Accommodations For Common MS Symptoms**

#### Symptoms

Fine motor impairment

#### **Gross motor impairment**

#### Accommodations

- Provide alternate computer & telephone access
- Writing and grip aids
- Ensure work-site & work-station are accessible
- Adjust desk height for wheelchairParking close to work-site
- Use scooter for long distances
- Job restructuring to allow tasks to be performed in sitting position

Vision difficulty

- Increase font size & use accessibility computer features
- Install proper lighting
- Glare screen



### Accommodations For Common MS Symptoms

#### **Symptoms**

**Bladder and bowel problems** 

Speech problems

Chronic pain

#### **Accommodations**

- Work space close to restroom
- Flexible work schedules, allow for frequent breaks
- Home-based work options
- Use adaptive computers, explore assistive technology
- Use more written communication through email & fax
- Flexible work schedule
- On-site rest areas for meditation or other pain-reducing techniques





- 34-year-old African American woman
- Diagnosed with MS 7 years ago; single, no children
- Successful career in interior design; owned her own interior decorating business for past 2 years
- Symptoms include vision problems, mobility challenges, tremor in dominant hand
- After much soul-searching, decided to close business due to impact of symptoms
- Thought a lot about transferrable skills and ways to still be connected to the artistic/creative field





## Patty, continued

- Focused job search on office manager-type jobs, but in creative environments
- Ultimately was hired as Office Administrator for an architecture firm
- Surrounded by creative people, familiar with blueprints, various people involved in the process
- Accommodations including using computer for note- taking & assistive technology (voice recognition software), which also assisted with tremor
- Felt great sense of involvement/integration with firm, appreciation for creative arts
- History of being self-employed allowed increased responsibility





### Martina

- 36-year-old Hispanic woman recently diagnosed with MS
- Teaches high school history
- Initial symptoms include numbress & tingling, fatigue, problems with memory & thinking,
- Becomes depressed, withdrawn, angry
- Consults with a psychologist at the MS treatment center (bribed by her partner & friends with a beer)
- Begins a regimen of talk therapy & antidepressant medication





### Martina, continued

- Discloses to her employer & requests/receives accommodations:
  - A/C in the classroom
  - Teacher's aide
- Discloses to her students and engages their help
  - Writing on the blackboard
  - Helping her with word-finding
  - Starting an MS Walk team in the community
- Receives complete support from administration, fellow teachers, students and parents
- Eventually becomes president of the teachers' union





# **Tips for Tough Times**

- Don't get defensive
- Have back-up plans
- Be flexible "win-win"
- Do your homework
- Tap into legal/protection resources
  - Equal Employment Opportunity Commission (EEOC)
  - Fair Employment Practice Agencies (FEPA)
  - Job Accommodation Network (JAN)
  - National MS Society



### Michael

- 43-year-old Caucasian man
- Diagnosed with MS 15 years ago
- Married, one daughter 10 years-old
- Works as hospital administrator



- Symptoms include fatigue, cognitive issues, balance problems
- Moved from small practice to larger hospital for increased employer-sponsored benefits
- MS symptoms now becoming more difficult to manage



## Michael, continued

- Current employer offered comprehensive benefits, e.g. short-term and long-term disability
- Explored all accommodations possible, including reassignment to another job; ultimately separated from the workforce
- Needed to exhaust short-term disability and FMLA
- Approved for long-term disability and applying for Social Security Disability Insurance (SSDI)





## **Impact On The Family**

- Family is also acknowledging losses & dealing with grief/loss
- Employment changes may shift family roles
  - Maintaining the "family rhythm"
  - Swapping responsibilities
  - Engaging help when needed
- Maintaining balance in the partnership
  - With each person, giving and receiving
  - Ensuring that each person feels like a valued, contributing member to the household
- Ensuring financial stability
  - Financial planning for the unpredictable future





### **Useful Resources**

### National MS Society Employment Information Website <u>http://www.nationalMSsociety.org/employment</u>

### National MS Society MS Navigator Benefits and Employment Services <u>EmploymentQuestions@nmss.org</u> or Call 1-800-344-4867



### **Useful Resources**

#### Information for Employers



The Win-Win Approach to Reasonable Accommodations



Working with MS INFORMATION FOR EMPLOYEES LIVING WITH MS





### **Useful Resources**

Job Accommodation Network Practical Solutions • Workplace Success

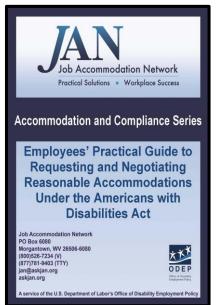
#### Accommodation and Compliance Series

Employees with Multiple Sclerosis

Job Accommodation Network PO Box 6080 Morgantown, WV 26506-6080 (800)526-7234 (V) (877)781-9403 (TTY) jan@askjan.org askjan.org

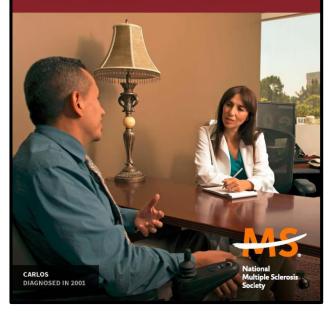


A service of the U.S. Department of Labor's Office of Disability Employment Policy



#### Applying for Social Security Disability Benefits

A Guidebook for People with MS and their Healthcare Providers For more information, visit nationalMSsociety.org/SSDGuide





Programs



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### **MS Path 2 Care**

An initiative to empower people affected by MS to be active partners in their healthcare experience.

Visit www.MSPath2Care.com to learn more about the importance of shared decision making in MS care, and to hear important tips directly from people living with MS, their support partners, and MS specialists.

MS Path 2 Care is brought to you in partnership with:



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### When Changes in Mood or Thinking Impact Daily Life

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