# Employment of People With Multiple Sclerosis

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## Introduction

- This discussion will focus on multiple sclerosis (MS), a disability whose nature and impact creates extraordinary challenges to employment. The discussion will include:
  - Description and incidence
  - Manifestation and functional limitations
  - Effects on employment
  - Attitudes towards employment
  - Benefits of employment
  - Challenges
  - Accommodations
  - Alternative employment
  - VRC roles

## Multiple Sclerosis (MS)

- Multiple sclerosis (MS) is a chronic, often disabling disease of the central nervous system.
  - Brain
  - Spinal cord
  - Optic nerves
- Demographics
  - More common among people of northern European ancestry
  - More women than men affected
  - Most diagnoses between age 20 to 50
- Incidence
  - 2.5m worldwide
  - 1m in USA

## MS and Employment

- High unemployment rate
  - 90% are employed at diagnosis
  - 30% are working five years after diagnosis
- Desire to work among PwMS
  - A primary unmet need
  - 75% of those unemployed would like to work
  - About 50% did not want to stop working or change jobs
  - 58% did not want to reduce work
- Reasons for unemployment
  - Functional limitations
  - Misinformation/Lack of information

## Benefits of Working

- Why do PwMS want to work?
  - Self actualization
    - Self accomplishment
  - Independence
    - Economic/Social
  - Quality of life
    - Emotional, social, physical, wellbeing
  - Identity
  - Social relationships
  - Psychological
    - Meaning/Purpose
    - Mental health

## Challenges to Employment

- Nature of disease
  - Common MS symptoms pose significant limitations
    - Vision
    - Speech
    - Mobility
    - Fatigue
    - Bladder/bowel control
    - Cognition
  - Unpredictable course
    - Unpredictable flare-ups and remissions
- Presence of (MS) triggers
  - Stress, Heat, Fatigue, Infections

## Challenges to Employment Pt. 2

#### • Employment Policies

- Poor or no disability benefits
- Part-time/Full-time hour requirements
- Employer unwilling/unable to provide accommodations
- Lack of Planning
  - Failure to anticipate and prepare for disease progression
- Lack of Support
  - Person with MS does not seek help on time
  - State agency may not have the needed funds

### Accommodations

- Flexible schedule
  - Allow for atypical work hours if possible
  - Non-rigid attendance requirements
    - Allow Telecommuting
- Modified Duties
  - Low stress, non-urgent tasks
  - Consider disease limitations
- Flexible Workplace
  - Allow PwMS to consider alternative positions
  - Allow/Provide additional training

### Accommodations Pt. 2

- Tools and Assistive Devices
  - Adjustable furniture
    - Decrease physical stress
  - Low tech devices
    - Magnifier, calendar/organizer, daily task list, etc.
  - High tech devices
    - Voice recognition devices, speech to text, etc.
- Mobility Aids
  - Scooter,
  - Stair Assist
  - Grab bars, etc.

## Role of VRC

#### • Advising

- On MS and employment issues
- Accommodations
- ADA
- Planning
  - Alternative positions,
  - Additional training
- Consultation/Advocacy
  - Educating employer
  - Negotiating alternative positions
- Evaluation
  - Vocational assessment
  - Job descriptions
- Placement
  - Outside employment or Work at Home

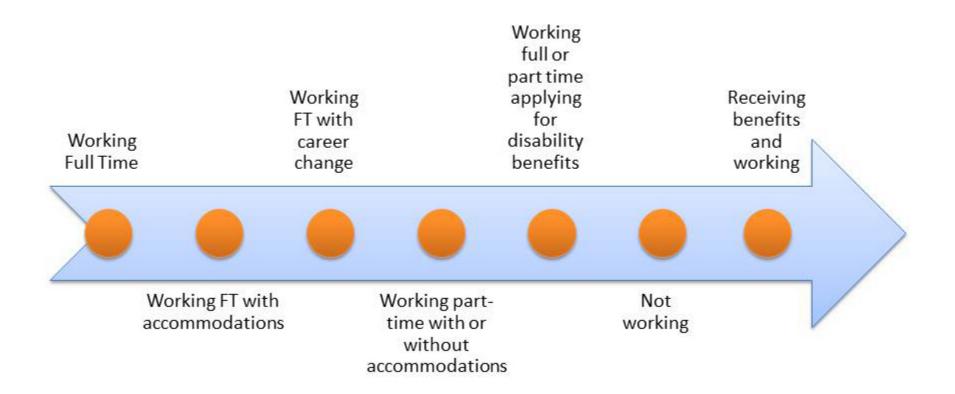
## New/Different Employment

- Similar job, new employer
  - New employer may offer accommodations
    - PwMS decides when to seek employment
    - PwMS decides what to disclose at interview
- Career change
  - Vocational evaluation
  - Consider residual, transferrable skills
- Self-employment
  - Entrepreneurship
- Work from Home

## Work from Home

- Explore re-employment with previous employer
  - Trainer, recruiter, customer Service
- Test self for requisite skills
  - Work at Home Assessment (Organizational and computer skills)
- Carefully consider options
  - SSI/SSDI Work-at-home jobs
  - Call Center Jobs (Rat Race Rebellion. Alpine Access, Convergys, West at Home)
  - Virtual Assistants (Internet Virtual Assistants Association, Internet Girl Friday)
  - Non-phone jobs (Fexjobs, Google Jobs, Working Solutions, Click N Work)
  - Internet Researchers/Evaluators (Butler Hill, Leapforce, Lionbridge)
  - Others: (VIPKID, TTEC, Intuit, Dell, UnitedHealth Group, Aetna, BroadPath Health, Kaplan)

## Employment of PwMS



#### Resources

- National Multiple Sclerosis Society
- Job Accommodations Network (JAN)
- The Multiple Sclerosis Association Of America: MSAA
- LiveWiseMS
- Multiple Sclerosis Foundation
- Multiple Scleriosis International
- Myelin Repair Foundation
- Multiple Sclerosis Trust

#### Questions

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