Employment of People With Multiple Sclerosis

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UNT-WISE Webinar Presentation
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 (Flexjobs, 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

- Working Full Time
- Working FT with career change
- Working full or part-time applying for disability benefits
- Receiving benefits and working
- Working FT with accommodations
- Working part-time with or without accommodations
- Not working
Resources

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


