

Mellen Center Approaches: Disability issues.

Should an individual stop working after receiving an MS diagnosis?

Receiving the diagnosis of MS certainly is not a reason to stop working, nor is there any immediate reason to advise one's employer about the diagnosis. There are many financial, health insurance and social reasons to maintain work as long as possible and most MS patients are able to work for many years after their diagnosis. When individuals develop specific symptoms that interfere with their ability to perform some aspect of their regular duties, it is important to discuss that with their MS-care team. Many symptoms are readily manageable with medication and rehabilitative interventions. Sometimes specialists such as an ophthalmologist, occupational therapist, physical therapist, neuropsychologist, or rehabilitation specialist can suggest specific interventions that allow continued work.

In cases where a combination of symptoms or a particular symptom are difficult to treat and work becomes difficult, it is suggested that persons with MS advise their employer of the MS or the specific symptom (depending on their comfort level with their employer), review the job successes they have had, describe the problem they are having and suggest some sort of job modification. If this is not possible and the person with MS is not able to continue working, then this is when they should begin seeking disability assistance.

What should I know about job accommodations?

We try to support our patients working as long as they possibly can. At times, continuing in a job requires reasonable accommodations on the part of the employer. If this is the situation, we recommend that the person with MS advise their employer of the need for accommodation and the symptom that requires this or the diagnosis that requires this, whichever they are comfortable with.

For useful guidelines on to when to disclose the diagnosis of MS in the workplace, go to:

<http://www.nationalmssociety.org/living-with-multiple-sclerosis/employment/disclosure/how-much-info/index.aspx>

As long as the person with MS is able to maintain key elements of their job, the Americans with Disabilities act requires the employer to comply with accommodations. If the needed accommodations are expensive or require work site modifications, a referral to the state office of vocation and rehabilitation should be considered. These state agencies are charged with assisting individuals with disabilities to maintain or retrain for continuing work. The Bureau of Vocational Rehabilitation is a resource for such issues.

What resources are available if a person is unable to work for a brief period of time?

If a person is experiencing new symptoms or recovering from an exacerbation they may need to be away from work for a period of days or weeks. Most workers use vacation days to cover this time away and may have as part of their employee benefit package a paid short term disability that pays a portion of their income. It is important that individuals with MS become familiar with the type of short-term disability they have through their employer. For individuals who run out of vacation days or don't have employer-paid short-term disability, the Family and Medical Leave Act assures that covered employees have a total of up to 12 work-weeks of unpaid leave during any 12-month period for any one of several reasons including an individual's own serious health conditions.

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Where does the doctor or treating health care practitioner come in?

Whether for short- or long term-disability (see next question), the health care provider is an important link in the documentation for disability. The person with MS should make clear what symptoms are interfering with the ability to work and ask their health care provider to document these symptoms in the clinical notes. The health care provider can write letters or notes about the patients diagnosis and limitations which may be used in a disability proceeding. The health care provider does not determine if the person with MS is disabled, however. This is up to the specific disability carrier to ultimately determine after reviewing the facts of the case.

What happens when a person becomes permanently disabled from work?

Many invisible symptoms and aspects of the work environment may make it difficult for health care providers to determine an individual's work ability during the course of a routine clinic visit. Patients should be encouraged to discuss this issue with the health care provider when work becomes an issue. It is important to address this issue before poor performance interferes with work. When persons with MS face the decision to apply for permanent disability it is important for their health care team to provide the support and documentation to guide them through this process.

Most individuals who have worked do count on Social Security Disability (SSDI) as their source of income, which is administered by the Social Security Administration (SSA), but there are a number of other types of disability listed below.

Defining Disability: Based on the SSA publication, Disability Evaluation under Social Security 2003, disability is defined as "The inability to engage in any substantial gainful activity by reason of medically determinable physical or mental impairment(s) which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months".

Long Term Disability options all have different criteria to trigger benefits:

- Social Security Disability Income (SSDI) – for disabled workers who have earned enough work credits to be eligible and are unable to perform any gainful work. One work credit is defined as part time or full time work with Social Security taxes paid for a period of 3 months. A total of 20 work credits must be earned in the past 10 years to be eligible (20 out of 40 possible quarters).
- Supplemental Security Income (SSI) – for disabled individuals who are indigent.
- Private disability policies – privately held policies with specific criteria for disability. These ideally protect the holder if they are unable to perform their specific job, not any job.
- Ohio Public Employees (OPERS) – coverage for Ohio public employees.

What type of Evaluation/Consultation should the clinical team consider?

- Potentially a referral to social work, which can assist with determining the appropriate option for disability, the application process, and possible alternatives (e.g. Bureau of Vocational Rehab).
- "Residual Functional Capacity" may be determined, which includes quantifying a claimant's ability to perform physical tasks (lifting, carrying, walking, bending, sitting, etc). This also includes assessment of mental capacity (cognitive, behavioral, thought processing, concentration, etc).
- Physical Therapy performs the Functional Capacity Evaluation (FCE)
- Neuropsychology performs the mental capacity assessment*
- Consider other referrals such as Ophthalmology to help quantify visual capacity.

**Note that the neuropsychological assessment battery typically conducted when ordered by the SSA may not include a thorough evaluation of many common cognitive issues associated with MS. If cognition is considered the primary source of disability, evaluation by a neuropsychologist with expertise in MS is recommended.*

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Who determines if a patient is disabled?

- The clinical team helps gather the information that is used to help determine a claimant's ability to work or, alternatively, to assist with the disability application. The final determination is made by the insuring entity (SSDI, etc), not by the clinical team.
- Individuals initiate a Social Security Disability application by initiating an application on line <http://www.ssa.gov/> or by phone, 1-800-772-1213.
- The National Multiple Sclerosis Society has an excellent hand book that describes the disability application process <http://www.nationalmssociety.org/government-affairs-and-advocacy/government-programs/social-security-disability/index.aspx>
- Important points for SSDI applicants
 - At any time along the application process, if a person receives a denial notice it is essential that they follow instructions on the back of that notice about how to appeal the denial. Failure to do so will result in restarting the application process.
 - Individuals applying for disability often ask if they need a lawyer. In the case of SSDI, a lawyer can have very limited influence on a disability determination until they have been denied twice. The next level of review is with an adjutant law judge and a lawyer can be helpful in preparing and representing a person at this review.

What is the criteria for disability?

The criteria varies widely amongst the different insuring entities, but in general most privately held disability policies insure claimants if they are unable to perform their current job. SSDI tends to have the most strict criteria for approval as SSDI only provides benefits if you are unable to hold any job that would provide a consistent monthly income of \$980* or more (*financial limit for 2009).

More specifically, SSDI defines disability under the diagnosis of Multiple Sclerosis as including one or more of the following:

- A. Significant and persistent disorganization of motor function in two extremities, resulting in sustained disturbance of gross and dexterous movements, or gait and station

- 11.00 C. Persistent disorganization of motor function in the form of paresis or paralysis, tremor or other involuntary movements, ataxia and sensory disturbances (any or all of which may be due to cerebral, cerebellar, brain stem, spinal cord, or peripheral nerve dysfunction) which occur singly or in various combinations, frequently provides the sole or partial basis for decision in cases of neurological impairment. The assessment of impairment depends on the degree of interference with locomotion and/or interference with the use of fingers, hands, or arms.
- B. Visual or mental impairment as described under the criteria listed
 - a. Impairment of Visual Acuity. Remaining vision in the better eye after best correction is 20/200 or less.
 - b. Contraction of Peripheral Visual Fields in the Better Eye.
 - A. To 10 degrees or less from the point of fixation; or
 - B. So the widest diameter subtends an angle no greater than 20 degrees; or
 - C. To 20 percent or less visual field efficiency.
 - c. Loss of Visual Efficiency. The visual efficiency of the better eye after best correction is 20 percent or less
- C. Significant, reproducible fatigue of motor function with substantial muscle weakness on repetitive activity, demonstrated on physical examination, resulting from neurological dysfunction in areas of the central nervous system known to be pathologically involved by the multiple sclerosis process.

RESOURCE:

Disability Evaluation Under Social Security – January 2003, Social Security Administration Office Of Disability, SSA Pub. No. 64-039, ICN 468600, January 2003

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Per the disability benefit handbook from Ohio Public Employees Retirement System (OPERS), an employee is eligible for disability benefits (edited for brevity) if he/she:

1. Participates in the traditional pension plan
2. Is no longer on the payroll as a result of a permanent disabling condition
3. No more than 2 years have passed since contributing service in the plan has terminated
4. Not receiving retirement under any OPERS plan
5. Expects his/her condition to last >12 months
6. Cannot perform the duties of the OPERS job

What about the patient who has 'hidden symptoms' of MS?

Documenting disability for patients with 'hidden symptoms' of MS may be more difficult than for those with measurable deficits. Symptoms such as pain, fatigue, and cognitive impairment are often not seen on standard neurological examination. It is important to document the presence, quality, location, timing, exacerbating and relieving factors, and treatments for pain, as well as some evaluation of the relationship with MS. For fatigue, documenting severity and how this interferes with functioning may be helpful. There are scales for fatigue that also may be useful such as the Modified fatigue impact scale.

<http://www.nationalmssociety.org/for-professionals/researchers/clinical-study-measures/mfis/index.aspx>

Neuropsychological assessments, particularly repeated over time, are very helpful in objectively documenting deficits that do not show up in routine bedside assessment.

What can patients do to facilitate this process?

1. Document their different symptoms.
2. Concisely state how their symptoms affect ability to work.
3. Document what attempts at accommodation have been made.
4. Document what would help continue current employment.
5. If presently a stay at home parent and planning to apply, make sure that the 2 year window has not elapsed (See above).

Once a person is determined disabled for any type of long term disability; will their eligibility ever be re-evaluated?

Some private insurance plans require reevaluation on a regular basis. It is important to continue to file this paperwork on a timely basis and the person with MS should make sure that they have forwarded it to the appropriate health care provider to fill out The SSA, on occasion, may also conduct a re-evaluation.

What else do I need to know about maintaining health insurance when disabled?

Insurance benefits can be lost once the person with MS stops working. It is important to encourage patients maintain insurance through with their employer's COBRA benefits if they can afford the cost after they have stop working. Two years after a person is approved for SSDI disability, health coverage will be provided through Medicare. In the meantime, your patients will need to seek alternative sources of coverage. Non-profit hospitals also have charity care programs for people who have lost health coverage and fall under certain income guidelines. Advise your patients to Check with a financial counselor to see if if they qualify. Some medications can be obtained through specific programs either with the manufacturer or with non profit agencies such as The National Organization for Rare Diseases (NORD). Encourage your patients to investigate such support.

RESOURCES:

The national MS society has extensive information on these topics as well as counselors with specific training in disability issues.

See for example:

National MS Society has a variety of resources. Can search under 'disability' or go to

<http://www.nationalmssociety.org/living-with-multiple-sclerosis/insurance-and-money-matters/index.aspx>

Americans with Disabilities Home page

<http://www.ada.gov/>

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