Recent studies indicate that nearly 1 million people in the U.S. are living with multiple sclerosis (MS). Because MS is most often diagnosed in people between the ages of 20 and 50, the majority are diagnosed during their most productive years of employment. Understanding MS and how it affects your employees can help maintain productivity and retain valuable workers.
What is multiple sclerosis?

Multiple sclerosis is a chronic autoimmune disease that affects the central nervous system, including the brain, spinal cord and optic nerves. It is not contagious. The cause of MS is unknown, but it is thought to be a combination of genetic predisposition and exposure to an unknown environmental factor, like a virus or bacteria.

When a person has MS, their immune system attacks myelin, a protein that surrounds and protects the nerve cells in the central nervous system. As myelin erodes, it distorts or disrupts the signals traveling through the central nervous system. Which nerves are affected and how badly the myelin is eroded determine a person’s symptoms.

Symptoms of MS

Symptoms vary from person to person but can include:

- Visual disturbances
- Extreme fatigue
- Loss of coordination
- Weakness or paralysis
- Numbness
- Muscle stiffness and pain
- Trouble with speech
- Problems with bladder or bowel control
- Mood changes
- Memory problems or other cognitive changes

Symptoms can be mild or severe.
Types of MS

There are four main types of MS that correspond to the course the disease takes. No one can predict what course a person’s MS will take.\(^5\)

- **Clinically Isolated syndrome (CIS),** where a person has had one episode of MS-like symptoms caused by a brain lesion – but not everyone with CIS goes on to develop MS.
- **Relapsing-remitting (RRMS),** where there are periods of time when symptoms worsen severely, then abate – sometimes completely. Times when symptoms lessen or disappear are called remissions.
- **Secondary progressive (SPMS),** where the disease starts as relapsing-remitting, then begins to steadily worsen within about 10 years.
- **Primary progressive (PPMS),** where symptoms steadily worsen from the time of diagnosis, without remissions or relapses.

Because of the variation in disease types and because one cannot predict when an exacerbation will occur, which nerves will be affected or how severely they’ll be affected, MS is different from person to person and even from one attack to the next.

Medications are an important part of managing MS. Oral, injected and infused disease-modifying therapies delay or slow the progression of the disease, reduce the number of relapses and even limit further myelin deterioration. Steroids can shorten relapses. Other medications are used to treat the many debilitating symptoms of MS.

Drugs to treat multiple sclerosis and manage symptoms

<table>
<thead>
<tr>
<th>Disease-modifying therapies</th>
<th>Injectable medications</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Avonex (interferon beta-1a)</td>
</tr>
<tr>
<td></td>
<td>Betaseron (interferon beta-1b)</td>
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<tr>
<td></td>
<td>Copaxone (glatiramer acetate)</td>
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<tr>
<td></td>
<td>Extavia (interferon beta-1b)</td>
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<tr>
<td></td>
<td>Glatiramer Acetate Injection</td>
</tr>
<tr>
<td></td>
<td>(glatiramer acetate — generic equivalent of Copaxone 20 mg and 40 mg doses)</td>
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<tr>
<td></td>
<td>Glatopa</td>
</tr>
<tr>
<td></td>
<td>(glatiramer acetate — generic equivalent of Copaxone 20mg and 40mg doses)</td>
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<tr>
<td></td>
<td>Plegridy (peginterferon beta-1a)</td>
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<tr>
<td></td>
<td>Rebif (interferon beta-1a)</td>
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<tr>
<td></td>
<td>Oral medications</td>
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<tr>
<td></td>
<td>Aubagio (teriflunomide)</td>
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<tr>
<td></td>
<td>Gilenya (fingolimod)</td>
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<tr>
<td></td>
<td>Tecfidera (dimethyl fumarate)</td>
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<tr>
<td></td>
<td>Infused medications</td>
</tr>
<tr>
<td></td>
<td>Lemtrada (alemtuzumab)</td>
</tr>
<tr>
<td></td>
<td>Novantrone (mitoxantrone)</td>
</tr>
<tr>
<td></td>
<td>Ocrevus (ocrelizumab)</td>
</tr>
<tr>
<td></td>
<td>Tysabri (natalizumab)</td>
</tr>
<tr>
<td></td>
<td>Managing exacerbations or relapses</td>
</tr>
<tr>
<td></td>
<td>High-dose intravenous Solu-Medrol (methylprednisolone)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Managing symptoms</th>
<th>Bladder problems</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Botox (onabotulinumtoxin A)</td>
</tr>
<tr>
<td></td>
<td>DDAVP Nasal Spray (desmopressin)</td>
</tr>
<tr>
<td></td>
<td>Detrol (tolterodine)</td>
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<tr>
<td></td>
<td>Ditropan (oxybutynin), Ditropan XL</td>
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<tr>
<td></td>
<td>Enablex (darifenacin)</td>
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<tr>
<td></td>
<td>Flomax (tamsulosin)</td>
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<tr>
<td></td>
<td>Hytrin (terazosin)</td>
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<tr>
<td></td>
<td>Minipress (prazosin)</td>
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<tr>
<td></td>
<td>Myrbetriq (mirabegron)</td>
</tr>
<tr>
<td></td>
<td>Oxytrol (oxybutynin)</td>
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<tr>
<td></td>
<td>Pro-Banthine (propantheline)</td>
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<tr>
<td></td>
<td>Sanctura (troxipium chloride)</td>
</tr>
<tr>
<td></td>
<td>Topranil (imipramine)</td>
</tr>
<tr>
<td></td>
<td>Vesicare (solifenacin succinate)</td>
</tr>
</tbody>
</table>

Infection

| Bactrim; Septra (sulfamethoxazole) |
| Cipro (ciprofloxacin) |
| Macrodantin (nitrofurantoin) |
| Hiprex (methenamine) |
| Pyridium (phenazopyridine) |
### Managing symptoms

#### Bowel dysfunction
- Colace (docusate)
- Dulcolax (bisacodyl)
- Enemeez (docusate stool softener laxative)
- Fleet Enema (sodium phosphate)
- Mineral oil
- Metamucil (psyllium hydrophilic musiloid)
- Phillips Milk of Magnesia (magnesium hydroxide)
- Sani-Supp suppository (glycerin)

#### Depression
- Cymbalta (duloxetine hydrochloride)
- Effexor (venlafaxine)
- Paxil (paroxetine)
- Prozac (fluoxetine)
- Wellbutrin (bupropion)
- Zoloft (sertraline)

#### Dizziness and vertigo
- Antivert (meclizine)

#### Emotional changes
- Nuedexta (dextromethorphan + quinidine)

#### Fatigue
- Amantadine
- Provigil (modafinil)
- Prozac (fluoxetine)

#### Itching
- Atarax (hydroxyzine)

#### Pain
- Dilantin (phenytoin)
- Elavil (amitriptyline)
- Klonopin (clonazepam)
- Neurontin (gabapentin)
- Pamelor; Aventyl (nortriptyline)
- Tegetrol (carbamazepine)

#### Sexual problems
- Cialis (tadalafil)
- Levitra (vardenafil)
- Papaverine
- MUSE (alprostadil)
- Prostin VR (alprostadil)
- Viagra (sildenafil)

#### Spasticity
- Botox (onabotulinumtoxin A)
- Dantrium (dantrolene)
- Gablofen (baclofen [intrathecal])
- Klonopin (clonazepam)
- Lioresal (baclofen)
- Valium (diazepam)
- Zanaflex (tizanidine)

#### Tremors
- Laniazid — Nydrazid (isoniazid)
- Klonopin — Rivotril — Syn-Clonazepam (clonazepam)

#### Walking (Gait) Difficulties
- Ampyra (dalfampridine)

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Note: Under certain circumstances, some health care providers may use medications to treat MS that have FDA approval for other diseases — also called “off-label” use.

Managing MS — continued

Medication costs

Costs for some of these medications can be prohibitive, amounting to tens of thousands of dollars within months. Offering a robust pharmacy benefit plan that covers medications for MS and other chronic conditions protects the investment you’ve made in your employees over the years, keeping experienced and knowledgeable employees in the workforce longer and avoiding turnover-related costs.

Many specialty pharmacies provide a team to support employees who take medications to treat MS. Care managers may contact an employee to complete health assessments and monitor medication adherence. Pharmacists with specialized knowledge of MS may be available for questions about medications and medication side effect management. Specialty pharmacy care teams may also include a social worker or those who can assist with billing or medication assistance programs.

<table>
<thead>
<tr>
<th>Drug</th>
<th>Administration</th>
<th>Cost estimate per month</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avonex</td>
<td>Injectable</td>
<td>$8,150</td>
</tr>
<tr>
<td>Rebif</td>
<td>Injectable</td>
<td>$8,700</td>
</tr>
<tr>
<td>Plegridy</td>
<td>Injectable</td>
<td>$8,150</td>
</tr>
<tr>
<td>Betaseron</td>
<td>Injectable</td>
<td>$8,500</td>
</tr>
<tr>
<td>Extavia</td>
<td>Injectable</td>
<td>$7,560</td>
</tr>
<tr>
<td>Copaxone 20mg</td>
<td>Injectable</td>
<td>$8,500</td>
</tr>
<tr>
<td>Glatopa 20mg</td>
<td>Injectable</td>
<td>$6,400</td>
</tr>
<tr>
<td>Copaxone 40mg</td>
<td>Injectable</td>
<td>$7,000</td>
</tr>
<tr>
<td>Glatopa 40mg</td>
<td>Injectable</td>
<td>$6,200</td>
</tr>
<tr>
<td>Zinbryta</td>
<td>Injectable</td>
<td>$8,700</td>
</tr>
<tr>
<td>Gilenya</td>
<td>Oral</td>
<td>$5,500</td>
</tr>
<tr>
<td>Aubagio</td>
<td>Oral</td>
<td>$6,500</td>
</tr>
<tr>
<td>Tecfidera</td>
<td>Oral</td>
<td>$8,800</td>
</tr>
<tr>
<td>Tysabri</td>
<td>Infusible</td>
<td>$14,800</td>
</tr>
<tr>
<td>Lemtrada</td>
<td>Infusible</td>
<td>$125,000 in year 1; $78,000 each year after</td>
</tr>
<tr>
<td>Ocrevus</td>
<td>Infusible</td>
<td>$78,000 per year</td>
</tr>
</tbody>
</table>

Sources: reimbursementcodes.com and Goodrx.com, 2018
How MS affects employment

A 2016 survey by the Multiple Sclerosis International Federation found that about 17% of respondents with MS were no longer employed within three years of being diagnosed. Respondents listed fatigue, mobility issues, weakness and unpredictable workloads as the top factors preventing them from remaining employed. After those, the top employer-related issues included lack of time off when needed, lack of support at work, inaccessible facilities and a workplace that was too hot or cold, because even slight changes in core body temperature can cause temporary worsening of symptoms for those with MS. All of these issues may be addressed, usually with modifications to the employee’s workstation or schedule. With limited accommodations, many people with MS stay productive and remain at work.

When employers and employees cooperate to address any barriers to working, employers benefit by:

- Retaining their training investment in valuable, experienced employees.
- Avoiding recruitment and training costs.
- Reducing costs of temporary staff.
- Maintaining productivity.
- Enhancing workplace diversity.
- Ensuring they’re in compliance with legal requirements to provide reasonable accommodations to employees with disabilities.

According to recent U.S. studies, an estimated 300,000 people with MS need extra assistance at home, which is usually provided by family members. You may have employees who serve as care partners to family members with MS. Again, the unpredictability of the disease means that a person with MS may not need assistance for months or years, until an exacerbation occurs. Conversely, a care partner may be needed daily.

Caring for a family member with MS puts substantial stress on the care partner, causing poorer overall health. Compared with people who do not take care of someone with a chronic illness, care partners take more medications, have higher amounts of stress hormones and weaker immune systems, and are more susceptible to a host of health problems, from high blood pressure and heart disease to depression and anxiety.

Supportive employers can help reduce stress levels and mitigate some of these negative health effects. Open lines of communication, flexibility around work schedules and time off, and awareness and understanding of MS can help keep healthy, productive care partners in your workforce.
As with most situations at work and with life in general, open communication simplifies everything. From the top down, a culture of openness, inclusion and accommodation shows employees that they are valued, and you are committed to them. Aside from building a happy, loyal workforce, this creates a culture where employees feel safe disclosing a diagnosis like MS and sharing what they need.

How to create a culture of...

**Inclusion**

Make disability awareness training part of your employees’ annual education. Share information about your company’s illness and disability policies and programs. Employees must have confidence that any disclosure of an illness or disability will be met with support; ensure that managers get training to this end, as well.

**Communication**

Make sure your employees know they can voice their concerns and challenges to management without fear. Open lines of communication between an employee and their manager can help maintain productivity and continuity in the event of an illness or exacerbation of MS. Employees who know their voices will be heard are empowered to collaborate with their managers to find solutions that benefit the business and employee.

**Accommodation**

In general, look for hazards or design elements that could make your workplace difficult to navigate for a person with mobility issues. If an employee discloses a disability, listen carefully to their concerns and the accommodations they request; do not make assumptions about what they can or cannot do. If your employee isn’t sure how their challenge can be accommodated, some suggestions can be found on the next page.
## Accommodating employees with MS

Questions to consider when identifying accommodations for an employee with MS:

- What limitations is the employee experiencing?
- How do these limitations affect the employee and their job performance?
- What specific job tasks are problematic because of these limitations?
- What accommodations are available to reduce or eliminate these problems? Are all resources being used to determine possible accommodations?
- Has the employee with MS been consulted regarding possible accommodations?
- Once accommodations are in place, would it be useful to meet with the employee to discuss how things are going and determine whether additional accommodations are needed?
- Do supervisory personnel and employees need training regarding MS?

<table>
<thead>
<tr>
<th>If an employee is having trouble with ...</th>
<th>Consider these accommodations:</th>
</tr>
</thead>
</table>
| Activities of daily living, like attending work, working at full production or performing activities of daily living related to work | • Allow use of a service animal at work  
• Make sure the building is accessible  
• Move workstation closer to the restroom  
• Allow longer breaks  
• Connect employee with relevant resources from the community or your Employee Assistance Program |
| Cognitive impairment or trouble with memory | • Provide written job instructions, when possible  
• Prioritize job assignments  
• Allow flexible work hours  
• Schedule periodic rest breaks  
• Provide memory aids, such as schedulers or organizers  
• Minimize distractions  
• Allow a self-paced workload  
• Reduce job stress  
• Provide more structure |
| Fatigue/weakness | • Reduce or eliminate physical exertion and workplace stress  
• Schedule periodic rest breaks away from the workstation  
• Allow a flexible work schedule and flexible use of leave time  
• Allow work from home  
• Implement an ergonomic workstation design  
• Provide a scooter or other mobility aid if walking cannot be reduced |

Adapted from the Job Accommodation Network website, a service of the Office of Disability Employment Policy, U.S. Department of Labor, https://askjan.org/media/MS.html
If an employee is having trouble with... | Consider these accommodations:
--- | ---
Fine motor impairment, including using a mouse or keyboard, the physical act of writing, gripping or pinching objects, operating a vehicle | - Implement an ergonomic workstation design
- Provide alternative computer or telephone access
- Supply arm supports
- Offer writing and grip aids
- Provide a page turner and a book holder
- Supply speech-recognition software

Gross motor impairment, like operating machinery; climbing, lifting or carrying things; maintaining balance; sitting, standing or walking for long periods | - Modify the worksite to make it accessible
- Provide parking close to the worksite
- Provide an accessible entrance
- Install automatic door openers
- Provide an accessible restroom and break room
- Provide an accessible route of travel to other work areas used by the employee
- Modify the workstation to make it accessible
- Adjust desk height if a wheelchair or scooter is used
- Make sure materials and equipment are within reach
- Move workstation close to other work areas, office equipment and break rooms

Sensitivity to heat or cold | - Adjust worksite temperature
- Use cool vest or other cooling clothing during hot weather
- Move workstation to a warmer or cooler part of the worksite
- Use fan, air conditioner or personal space heater at the workstation
- Allow flexible scheduling and flexible use of leave time
- Allow work from home during hot or very cold weather

Speech impairment, such as difficulties in producing speech sounds or appropriate volume | - Provide speech amplification, speech enhancement or other communication device
- Use written communication, such as email
- Transfer to a position that does not require a lot of verbal communication
- Schedule periodic rest breaks

Vision impairment, like trouble seeing or reading | - Magnify written material using hand/stand/optical magnifiers
- Provide large print material or screen-reading software
- Control glare by adding a glare screen to the computer
- Install proper office lighting
- Allow frequent rest breaks

Activities related to caring for a family member with MS | - Offer flexible scheduling and flexible use of leave time
- Allow work from home during MS exacerbations
- Reduce or eliminate workplace stress when possible
- Refer to appropriate community services or your Employee Assistance Program
Disability programs: How they can help

Offering a robust suite of disability insurance plans can help your employees in the event that they are diagnosed with a chronic disease like MS. Some disability plans offer dedicated disability case managers (DCM) who handle the gathering of information from employees, human resources and physicians, and then coordinate resources and work with employees and management to create case-specific action plans and explore return-to-work opportunities. Dedicated DCMs assist employees through any transitions back to work or into long-term disability or Social Security assistance.

A DCM can also put employees and their families in touch with various resources, including vocational rehabilitation, legal and financial resources, and behavioral health counseling, to help them through some of the challenges commonly faced by those dealing with a serious medical diagnosis. Often, the vocational rehabilitation counselor can work with the employee, employer and physician to identify ways to help the employee stay at work through workplace accommodations and use of adaptive equipment.

Adapted from the Job Accommodation Network website, a service of the Office of Disability Employment Policy, U.S. Department of Labor, https://askjan.org/media/MS.html

Some disability benefit plans, such as Anthem’s Productivity Solutions, can offer a unique way to help employees manage their health through chronic illness, surgery, complicated injuries and pregnancy. Disability claims for conditions such as MS are referred to a health coach or medical nurse care manager. The health coach or nurse engages the employee in appropriate care management programs, collaborates with the disability case manager to develop a holistic care management and return-to-work plan, and stays in contact until 30 days after the employee’s return to work. The encouragement and assistance of a dedicated health coach or care manager helps to avoid repeat claims — so employees can get healthy and stay healthy.
Types of disability plans

These plans are available from Anthem with a variety of funding arrangements and are part of a complete benefits package that can attract top talent to your business.

**Short-term disability plans**

These plans typically pay 40% to 60% of the employee’s weekly salary, for a period that can range from a month to two years. Most plans pay benefits for 3 to 6 months, after which the employee would need to either return to work or transition to long-term or permanent disability.12

**Long-term disability plans**

These usually pay 50% to 70% of the employee’s weekly salary, starting after short-term plan benefits end. Some plan benefits last for five or 10 years and others continue until retirement age.13

**Long-term care insurance**

This helps to cover the cost of nursing facility care or in-home care in the event of a long-term illness disability.14

Adapted from the Job Accommodation Network website, a service of the Office of Disability Employment Policy, U.S. Department of Labor, https://askjan.org/media/MS.html
While MS is a devastating disease, more treatments are available now than ever before. With appropriate accommodations, many people with MS can remain at work. Your personnel are your most valuable assets, and learning how to accommodate employees who are dealing with MS protects the investment you’ve made in talent cultivation over the course of their tenure. An employer who is open-minded and flexible has the opportunity to work with their employees to build a culture of loyalty and trust, delivering immeasurable value to their business.

Resources for employees with MS and their employers

The Rehabilitation Services Administration of the U.S. supports vocational rehabilitation programs, including funding for training, home or workplace modifications and assistive technology to help people with disabilities stay productive and at work. Find more information online at rsa.ed.gov.

The Job Accommodation Network (JAN) is a service of the U.S. Department of Labor’s Office of Disability Employment Policy (ODEP). JAN provides free expert advice, including one-on-one guidance on workplace accommodations and the Americans with Disabilities Act (ADA). Find out more online at askjan.org.