

POPULATION SPECIFIC FACT SHEET

What to Know When Assisting a Consumer with Multiple Sclerosis

This fact sheet is intended to help Navigators identify what issues are unique to consumers with Multiple Sclerosis so that they can assist them as they make decisions related to their healthcare coverage.

Q1. What do I need to know about Multiple Sclerosis?

A. Multiple sclerosis is an unpredictable, often disabling disease of the central nervous system (brain, optic nerve and spinal cord), which interrupts the flow of information within the brain, and between the brain and the body. The disease is thought to be triggered in a genetically susceptible individual by a combination of one or more environmental factors. Anyone may develop MS but there are some patterns. While there is no way to predict with any certainty how a person's MS will progress, four basic disease courses have been defined: Relapsing-Remitting (85% of initial diagnoses); Primary Progressive (10%); Secondary-Progressive MS (often occurs following a period of Relapsing-Remitting disease); and Progressive-Relapsing (5%). Two to three times more women than men have been diagnosed with MS. Most people are diagnosed between the ages of 20 and 50, although an estimated 8,000 to 10,000 children under the age of 18 also live with MS, and people as old as 75 have developed it. Most people with MS have a normal or near-normal life expectancy. In fairly rare cases, complications of MS can shorten life, including infections of various kinds.

MS symptoms are variable and unpredictable. No two people have exactly the same symptoms, and each person's symptoms can change or fluctuate over time. One person might experience only one or two of the possible symptoms while another person experiences many more. MS can cause extreme fatigue, impaired vision, problems with balance and walking, numbness or pain and other sensory changes, bladder and bowel symptoms, tremors, problems with memory and concentration, mood changes and more. Emotional changes among persons with MS may be a reaction to the stresses of living with the disease as well as the result of neurologic and immune changes.

Q2. What type of health care providers does someone with Multiple Sclerosis need to have access to?

A. A neurologist is the type of doctor that diagnoses and treats MS, and some neurologists choose to specialize in treating MS. Additionally, a comprehensive MS care team may also include: nurse, rehabilitation specialists¹ (physiatrist, physical therapist, occupational therapist, speech/language pathologist), mental health specialists (psychologist and neuropsychologist, social worker), nutritionist, urologist, and primary care physician.

¹ <http://www.nationalmssociety.org/Treating-MS/Rehabilitation>

Q3. What are some of the prescription needs that someone with Multiple Sclerosis may have?

A. As of the summer 2015, thirteen U.S. Food and Drug Administration (FDA)-approved disease-modifying therapies² are available to reduce disease activity and disease progression for many people with relapsing forms of MS, including secondary-progressive and progressive-relapsing MS in those people who continue to have relapses. There is no currently available treatment for primary progressive forms of MS. Early and ongoing treatment with disease-modifying therapy is supported by a review of the available medical evidence as described in the Consensus on Disease-Modifying Therapies³ and may be useful when discussing treatment options with healthcare providers and advocating with insurers for access and coverage. Adhering to disease-modifying medication is a key element of treatment effectiveness.⁴ Navigators and Assisters should be aware that some MS disease modifying therapies are administered by self-injection, others are administered by infusion with the aid of healthcare provider(s), and still others are oral medications. As a result, MS therapies included on a health plan's formulary may be listed under 'prescription drugs', while others may be covered under a different category or as a medical benefit.

All of the MS disease modifying therapies are considered 'specialty pharmaceuticals' and can be cost—prohibitive for many people, including those with health insurance due to high co-insurance. Each of the manufacturers' of these agents supports patient financial assistance programs to help with the costs of these medications.⁵

MS relapses⁶ (or attacks) are caused by inflammation in the central nervous system that damages the myelin coating around nerve fibers. This damage slows or disrupts the transmission of nerve impulses and causes the symptoms of MS. Most relapses will gradually resolve without treatment. For severe relapses (involving loss of vision, severe weakness or poor balance, for example), which interfere with a person's mobility, safety or overall ability to function, most neurologists recommend treatment with corticosteroids. The most common treatment regimen is a three-to-five-day course of high-dose, intravenous corticosteroids to reduce inflammation and end the relapse more quickly. This regimen may or may not be followed with a slow taper of oral prednisone. Corticosteroids are not believed to have any long-term benefit on the disease. Medication options include: high-dose intravenous Solu-Medrol® (methylprednisolone)⁷; High-dose Deltasone® (prednisone)⁸; H.P. Acthar

²<http://www.nationalmssociety.org/Treating-MS/Medications#section-1>

³http://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/DMT_Consensus_MS_Coalition.pdf

⁴<http://www.nationalmssociety.org/Treating-MS/Medications/Adherence>

⁵<http://www.nationalmssociety.org/Treating-MS/Medications/Financial-Assistance-Programs>

⁶<http://www.nationalmssociety.org/Treating-MS/Managing-Relapses>

⁷<http://www.nationalmssociety.org/Treating-MS/Medications/Solu-Medrol>

⁸<http://www.nationalmssociety.org/Treating-MS/Medications/Deltasone>

Gel (ACTH)⁹ is an option for those who are unable to cope with the side effects of high-dose corticosteroids, have been treated unsuccessfully with corticosteroids, do not have access to intravenous therapy, or have trouble receiving medication intravenously because of difficulty accessing the veins.

In addition to medications to help modify the disease course and treat relapses, a wide variety of medications are used to help manage the symptoms of MS,¹⁰ including many not specifically indicated for use in MS. Common symptoms of MS that patients seek treatment for include: bladder problems, infections, bowel dysfunction, depression, dizziness and vertigo, emotional changes, fatigue, itching, pain, sexual dysfunction, spasticity, tremors, and walking difficulties (gait).

Q4. What type of therapies (physical, occupational, speech, etc.) and/or devices (durable, disposable, etc.) would someone with Multiple Sclerosis potentially require?

A. Rehabilitation specialists are often the persons to identify the tools and strategies that best meet each person's mobility and accessibility needs, keeping one active, productive and involved. Physical therapists, occupational therapists, speech/language pathologists, and physiatrists¹¹ can often restore and maintain function, manage symptoms, and identify appropriate tools and strategies to accomplish tasks and achieve goals.

Because MS is different for each person that has the disease the need for assistive technology, devices, and medical equipment varies widely. Some persons may have no needs for assistance; others may need to use a walker or cane for balance, while others may lose functioning in one or more parts of their body increasing their needs for assistive devices.

Q5. What other services and supports, which are not generally medically arranged therapies and devices, are typically required by persons with Multiple Sclerosis? Are these arranged and financed in some private health insurance plans or in some Medicaid programs?

A. Chore services, home care, support groups, therapy, home and vehicle modifications, therapeutic recreation, complementary and alternative treatments (CAM), including acupuncture, chiropractic care, and massage. CAM treatments are financed by some private health insurance plans and can sometimes be covered under Medicaid.

Q6. Are there any other unique medical needs that someone with Multiple Sclerosis should consider when evaluating a health plan?

⁹ <http://www.nationalmssociety.org/Treating-MS/Medications/H-P-Acthar%C2%AE>

¹⁰ <http://www.nationalmssociety.org/Symptoms-Diagnosis/MS-Symptoms>

¹¹ <http://www.nationalmssociety.org/Treating-MS/Comprehensive-Care/Deveoping-a-health-care-team>

A. Periodic magnetic resonance imaging (MRIs) are used to help diagnose MS, and are an important component of monitoring disease progression once a diagnosis has been made on an “as needed” basis. Proper assessments can be crucial to quality MS care, including neuro-psychological evaluations to assess cognitive impairments, home and workplace safety assessments by an occupational therapist and more. Periodic laboratory analyses to determine kidney function and other possible side effects of treatment are also recommended for patients on certain MS disease modifying therapies. Because heat and high temperatures can be associated with worsening of MS symptoms, patients often need air conditioning and cooling devices to help avoid exacerbations.

Q7. Are there any type of accommodations I should consider when I’m planning to meet with someone with Multiple Sclerosis?

A. People with MS can experience physical challenges that are easily seen (use of cane or wheelchair), but also may experience cognitive issues that limit their comprehension and short term memory. It is best to provide materials for individuals and families to take home, and to encourage note taking. People with MS may also experience vision issues (low vision, blurry vision) so it may help to offer the materials in large print or audio format.

Q8. Are there any resources you would recommend to obtain additional information about Multiple Sclerosis?

A. The National MS Society offers information, counseling and referral to community resources to at no cost to anyone seeking information about MS. 1-800-FIGHTMS/344-4867 (www.nationalmssociety.org). Also see: Multiple Sclerosis ‘Just the Facts’: <http://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/Brochure-Just-the-Facts.pdf>

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