

# Patients with Multiple Sclerosis

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## OBJECTIVES

After completing this program, the home health aide will be able to:

- » Define multiple sclerosis (MS) as a chronic progressive disease affecting the central nervous system
  - » List three common symptoms of MS
  - » Identify two findings home health aides should observe and report, and
  - » Point out that MS is usually a disease with remissions and relapses.
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## OVERVIEW

About 400,000 people in the United States have multiple sclerosis. The symptoms vary greatly from person to person and from time to time in one person. When symptoms are present, they often reduce the person's ability to perform activities of daily living (ADLs). During relapses, many patients with MS require assistance from home health aides. For that reason it is important that aides understand the basics of the disease as well as their role in providing care.

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## CONTENT

Read the Fact Sheet	15 minutes
Read the Case Study	10 minutes
Complete "Think About It"	10 minutes
Complete the Post-test	15 minutes
Feedback Session	10 minutes

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## SUPPLEMENTAL LEARNING ACTIVITIES

- » Obtain patient information from the National MS Society and distribute to participants. <http://www.nationalmssociety.org>
- » Arrange for a speech-language pathologist (SLP) to speak to participants. Have the SLP discuss some of the common speech and swallowing problems encountered in MS patients.
- » Call the local Multiple Sclerosis Society and arrange to have a person with MS speak with participants about living with the disease.
- » Arrange for a physical therapist to speak to participants about the gait problems common to MS patients. Ask the therapist to provide examples of assistive devices commonly used by the patients.
- » Distribute the agency's patient education materials on MS and discuss with participants.



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## THE FACTS

Multiple sclerosis (MS) is a disease of the central nervous system. The central nervous system includes the brain, spinal cord, and nerve fibers. A tissue called myelin surrounds different parts of the central nervous system. Myelin and the myelin sheath protect the nerve fibers and allow them to conduct to and from the brain the electrical impulses that make the body feel things and move.

When a person has MS, the myelin, myelin sheath, or even the nerve fibers themselves can become damaged and replaced by scar tissue. The damaged areas, known as plaques or lesions, prevent normal transmission of nerve impulses. The resulting problems with nerve conduction cause the various symptoms of MS.

No one knows exactly what causes a person to develop MS, although it is more common among women than among men. It is not contagious. While it is not directly inherited, there does seem to be some hereditary link. About 5% of MS patients have a brother or sister with MS. Approximately 400,000 people in the United States have MS and it most commonly begins between the ages of 20 and 40.

Most people with MS have periods of relatively good health and other periods of "flare-ups" when they have more symptoms. The good-health intervals are known as remissions and the symptomatic intervals are known as relapses.

MS is a chronic and progressive disease that worsens slowly over time. However, it is not considered a fatal disease and most patients will have a normal life span. Patients over time will become increasingly disabled but it is an important fact that only a fourth of the patients will need a wheelchair. The majority of patients do not become severely disabled.

There is no cure for MS, but there are many medications to treat symptoms. There are also promising new drugs that seem to delay disabilities and provide longer remissions.

## PATTERNS OF MS

Patients with MS tend to have certain clinical courses of the disease. Each course could be mild, moderate, or severe.

1. **Relapsing-remitting** is by far the most common diagnosis, with more than 85% of patients having this course. There are times of partial or total recovery after an attack.
2. **Secondary progressive** may be a second clinical course that follows relapsing-remitting. Attacks continue to occur, but each recovery is less than previous ones. At this point the patient is progressively declining.
3. **Primary progressive** is a course of MS in which the symptoms progressively occur without acute attacks. The patients do not experience recovery from the symptoms and become progressively more disabled. Only 10% of MS patients have the primary progressive course of illness.
4. **Progressive relapsing** is a rare course in which the progressive course brings new symptoms or acute attacks all along the way. It is a rare clinical course of MS, occurring in only 5% or less of MS patients.

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## SYMPTOMS

The symptoms of MS are not predictable. They often come and go, sometimes affecting one part of the body and sometimes another. They vary from person to person and even from time to time in the same person. It is the damage to the myelin sheaths that causes the symptoms, so the symptoms will be worse when the damage occurs and then improve as the damage repairs itself, then become worse again with further damage. Most symptoms will come and go, but some will be long lasting.

## EARLY SYMPTOMS

The early symptoms of MS include numbness and tingling, or pain, burning and itching in the arms, legs, trunk, or face. Often there is a loss of strength or dexterity in the hands. The person may notice some memory disturbances and have difficulty concentrating or paying attention. These symptoms are usually caused by myelin damage in the brain and may be present for quite a while before the person is diagnosed. Because they are rather vague symptoms, and may disappear for long periods of time, the person may not see a doctor about them.

## MOST COMMON SYMPTOMS

### **Numbness**

Numbness of the face, extremities, or other body parts is one of the most common symptoms of MS. It occurs so often that it is frequently the symptom that leads to the initial diagnosis. Unfortunately there are no medications to treat the numbness, but the symptoms often disappear on their own.

### **Dizziness**

Dizziness is a common symptom and may cause the person to feel lightheaded or unbalanced. Occasionally the person has vertigo, a condition that makes the person feel like the room is spinning around, but this is much less common. There are medications to help the dizziness.

### **Bladder problems**

About 80% of patients with MS will have bladder problems or dysfunction. MS often affects the nerve transmission to and from the bladder muscles. Urinary frequency, urgency, hesitancy, and incontinence may result. Sometimes the problem is that the bladder does not empty and urine is retained. There are medications that help bladder dysfunction, but many MS patients require intermittent catheterization or an indwelling catheter.

### **Bowel problems**

Constipation is common among patients with MS, although some patients may have diarrhea or incontinence. Bowel programs and good nutrition are helpful.

### **Mobility problems**

- **Extremity weakness** — the nerve conduction problems may cause the legs to be weakened and lead to problems with gait. Sometimes the weakness affects only one side but at other times both sides are affected.

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- Spasticity — nerve conduction problems can cause the muscles to become spastic and rigid. There are medications to help with muscle relaxation.
- Balance problems — sometimes an MS patient will have decreased balance which may cause him or her to stagger.
- Decreased sensation — severe numbness in the feet can cause mobility problems because the patient cannot sense where his or her feet are and may not be able to feel the floor.

## Visual problems

Patients with MS frequently have visual symptoms, but MS rarely causes blindness. There are several types of visual disturbances that may occur

- Optic neuritis — occurs when there are plaques along the optic nerve. It may cause blindness in one eye or the other, blurring, spots in the visual field or graying. The optic neuritis is usually self-limiting and there are medications to hasten recovery.
- Uncontrolled eye movement — results when the eyes make little quick jumping movements, either vertically or horizontally. Nystagmus is the medical term for the movements and they may impair vision.
- Double vision — occurs when the muscles of one eye are not coordinated with the muscles of the other. The images are not focused and the person sees “double.” Diplopia is the medical term for double vision.

## Speech disorders

Speech problems are fairly common in MS patients because of the lesions in the brain. There are varieties of problems that can result.

- Scanning — is a type of speech disturbance in which there are long pauses between words or even between syllables of the same word. The normal rhythm of speech is interrupted.
- Slurring words — usually results from weakness of muscles of the tongue, lips, and mouth rather than lesions in the brain. Sometimes the patient sounds as if he or she has a cold.

## Difficulty swallowing

Difficulty swallowing (dysphagia) can occur at any time but more frequently occurs in advanced MS. The person may have difficulty swallowing thin liquids or choke when eating foods with crumbly textures. MS patients who have speech disorders are more likely to have difficulty swallowing.

## Cognitive disorders

Cognitive disorders include decreased ability to reason, concentrate, and/or remember. About half of all MS patients will develop some cognitive disorders during the disease process. Like other MS symptoms, cognitive changes can vary a great deal. Memory seems to be the cognitive function most likely to be affected. It is important to keep in mind that while half of all MS patients develop some cognitive disorder, only five to ten percent develop severe cognitive disorders that interfere with everyday activities.

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## Temperature sensitivity

MS patients often have a temporary worsening of symptoms when the weather is hot and humid. In addition, symptoms tend to worsen when they take very hot showers or baths, get overheated from exercise, or have fevers. Cold weather can also cause worsening of some symptoms, especially spasticity. MS patients should avoid all temperature extremes if possible.

## Itching

Itching can occur as a symptom of MS. It can happen suddenly and is usually for only a brief period of time. It can happen over any part of the body. Unlike allergic itching, the itching from MS does not cause any redness or irritation at the site of the itching. The itching area appears normal.

## THE HOME HEALTH AIDE'S ROLE

The home health aide's role in care of MS patients will vary a great deal; just as the symptoms of the disease vary. In most instances, the nurse or therapist develops the assignment sheet based on the symptoms and needs of the patient as well as the clinical course of the disease. The home health aide's role includes:

### Assisting with personal cares

- » Provide assistance based on the assignment sheet. Allow the patient to assist as much as possible, and notify the supervisor if the patient appears to need additional help.
- » Make certain the shower or bath water is not excessively hot or cold. Keep the patient covered as much as possible and the temperature constant.
- » If the patient has difficulty swallowing, follow the assignment sheet in assisting with food and liquids. Keep in mind that the patient may have numbness and could bite the inside of the mouth or tongue without feeling it.
- » Provide catheter care as outlined on the assignment sheet.
- » Assist with any bowel program developed for the patient.

### Assisting with exercises

- » Time the exercises so that the patient is not overly tired.
- » Follow the assignment or therapy instruction sheet carefully. Notify the supervisor if you're unsure how to follow the exercise plan.
- » Do not "force" range of motion in joints that are spastic. Move slowly and in a relaxed manner.

### Assisting with ambulation and transfers

- » Encourage the use of assistive devices.
- » Be aware of any visual symptoms or balance problems the patient may be having that might interfere with ambulation.
- » Notify the supervisor if there are significant changes in ambulation.

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## Communication

- » Learn how to use any communication tools developed for the patient.
- » Do not ask several questions in rapid succession; provide sufficient time for the patient to answer questions.
- » If the speech is slurred, do not assume that you understand what the patient has said. Repeat slowly what you think was said and ask the patient if that is correct. If not, ask the patient to repeat the phrase or use another means of communicating, such as a pencil and paper.

## Observing and reporting

- » Because the symptoms of MS can vary, it is important for home health aides to observe for any new signs and symptoms and, if any are found, to report them to the supervisor.
- » It is important to observe the urine for color, odor, and clarity. Report any pain on urination, fever, or changes in urine characteristics since any of those could be symptoms of a urinary tract infection.
- » Observe the amount and consistency of the stool and report changes to the supervisor.
- » Carefully observe the skin during each visit and report changes to the supervisor.
- » Observe the patient's behavior and notify the supervisor of changes noted.

## KEY POINTS TO KEEP IN MIND

1. MS is a disease of the central nervous system and the symptoms will depend on what parts of the nervous system are affected at a given time.
2. MS is not a fatal disease. Although the disease is usually progressive, most patients will have a normal lifespan. Only patients with very severe MS have a somewhat shorter life span.
3. MS is almost always a disease in which there will be attacks of symptoms (relapses) and periods of recovery (remissions).
4. No two MS patients will have identical symptoms. In fact, the symptoms in one person will vary from time to time.
5. It is essential for home health aides to read and follow the assignment sheet carefully when working with MS patients.

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## CASE STUDY

Mrs. Palermo is forty-three years old. She was first diagnosed with multiple sclerosis (MS) fifteen years ago when she went to the doctor because she had a lot of numbness and tingling in her face, legs, and feet. Mrs. Palermo has been able to work in her job as an administrative assistant most of the past fifteen years. She takes a lot of medications, and her husband gives her injections once a week. She has had occasional problems with mobility and has had to use a cane sometimes. Then the problems would get better and she would not need any assistive device.

Two years ago she began having bladder problems and urinary retention. She learned to catheterize herself several times a day and was doing well until a month ago. A month ago, she developed a high fever and went to the hospital where she was diagnosed with a severe urinary tract infection. She was treated with antibiotics and the urinary tract infection was resolved. She became much more debilitated during the hospitalization and developed so much numbness in her hands she can no longer catheterize herself and has an indwelling foley. Her balance is much worse and she now requires a walker for ambulation. She is extremely tired all the time and must rest frequently.

Mrs. Palermo is receiving homecare for the first time since she was diagnosed with MS because she is not able to perform her own personal care without help.

## THINK ABOUT IT

- » Is Mrs. Palermo the age and gender of most MS patients?
- » Review the first paragraph and note the circumstances that are common to many MS patients.
- » Do you think any of Mrs. Palermo's symptoms are likely to improve? Why or why not?
- » What do you think will be some of the duties of the aides assigned to Mrs. Palermo?



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DIRECTIONS: READ EACH QUESTION CAREFULLY. THEN, DETERMINE THE BEST ANSWER. CHECK THE CORRESPONDING BOX ON YOUR ANSWER SHEET. DO NOT WRITE ON THIS POST-TEST.

1. Which of the following statements best describes multiple sclerosis (MS)?
  - a. MS is a disease that is always fatal.
  - b. MS is a chronic, progressive disease marked by periods of "flare-ups" and periods of recovery.
  - c. MS is a disease in which every patient will eventually have to use a wheelchair.
  - d. MS is a disease of the nervous system that affects men much more often than women.
  
2. Which of the following is not considered a common symptom of MS?
  - a. Nausea and vomiting
  - b. Numbness
  - c. Bladder problems
  - d. Mobility problems
  
3. MS is a disease of which body system?
  - a. The skin
  - b. The musculo-skeletal system
  - c. The digestive system
  - d. The central nervous system
  
4. Which of the following statements is true?
  - a. There is a cure for MS.
  - b. MS always follows the same course in all patients who have it.
  - c. Most MS patients will have bladder problems or dysfunction.
  - d. MS is a contagious disease spread through direct contact with patients.
  
5. Which of the following is an important finding that the home health aide should report to the supervisor?
  - a. The patient's urine is cloudy and foul smelling.
  - b. The patient had a bowel movement after the bowel regimen.
  - c. The patient tolerated the bath well.
  - d. There are no changes in the patient's skin.
  
6. Because MS is a chronic disease, the patient's current symptoms will never improve.
  - a. True
  - b. False

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POST-TEST, PAGE 2

7. Which of the following symptoms may lead to mobility problems for MS patients?
- a. Spasticity of the muscles
  - b. Numbness of the feet
  - c. Weakness in the legs
  - d. All of the above
8. Which of the following is not true about exercises for MS patients?
- a. All MS patients will have the same exercise program.
  - b. The home health aide should notify the supervisor if he or she is unsure how to follow the exercise plan.
  - c. Exercises should be done when patients are not overly tired.
  - d. It is especially important not to "force" range of motion if the joints are spastic.
9. What causes the symptoms of MS?
- a. Plaques or lesions that prevent normal nerve conduction
  - b. Small clots in the blood vessels that prevent normal blood flow
  - c. Pressure in the brain from swelling
  - d. Excessively high blood sugar
10. MS primarily affects the elderly and is rarely found in patients younger than 50.
- a. True
  - b. False

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