
MULTIPLE SCLEROSIS
DISEASE ACTIVITY
matters
A GUIDE TO MULTIPLE SCLEROSIS
SIGNS AND SYMPTOMS

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IMPORTANT – PLEASE READ

Information provided in this booklet is for educational purposes only. It is not intended to replace the advice or guidance of a professional healthcare practitioner or as a substitute for medical care. Contact a qualified healthcare practitioner if you have any questions concerning your care.

INTRODUCTION

Multiple sclerosis (MS) is an autoimmune disorder in which a person's immune system causes inflammation and tissue damage in the central nervous system (CNS) – the brain, spinal cord and optic nerve. When inflammation flares up, it interrupts the signals travelling along the nerves. This can cause a range of symptoms depending on which part of the CNS is being affected.

The inflammation that occurs in MS is known as ***disease activity***. This disease activity may be experienced as MS symptoms, or it may be "silent", detectable only with a magnetic resonance imaging (MRI) scan. When considered together, symptoms and MRI results provide you and your healthcare team with important clues about your MS.

Your doctor may prescribe medication to reduce the occurrence of inflammation and tissue damage in the hope that this will lessen disability in the years ahead. Ongoing disease activity – worsening symptoms, a relapse or new lesions on an MRI – may indicate that your treatment is not fully effective in managing your MS.

To get a complete picture of your MS requires a close collaboration between you and your healthcare team. MS symptoms are something you experience but they are often undetectable to others. Conversely, you may be unaware of MS lesions in your CNS that your doctor and MS nurse can see on your MRI scan. So it is important that you, your doctor and your MS nurse share what you know about your MS disease activity to ensure that you receive the care you need.

This booklet has been developed to help you inform your doctor, MS nurse and other members of your MS care team about the symptoms you are experiencing. It also explains what an MRI can tell you about your MS. The hope is that in identifying disease activity early, you and your healthcare team can develop ways to relieve your symptoms and manage your MS.

MS SYMPTOMS

Disease activity can cause MS symptoms that affect many parts of your body. Some common symptoms that may indicate that your MS is active include:

- **SENSORY SYMPTOMS:**
  such as numbness, tingling ("pins and needles") or pain. For example, numbness may start in the hands or feet and then spread throughout a limb or to other parts of your body. Some people also experience what feels like an electric shock in their neck and spine (called Lhermitte's symptom) when they move their head forward.

- **MOTOR (MUSCLE) SYMPTOMS:**
  such as weakness or spasticity (stiffness or spasms). Changes in muscle control can affect different body functions, such as walking ability, writing ability and bowel/bladder function.

- **VISION PROBLEMS:**
  such as blind spots or blurriness (in one eye), loss of colour vision, pain when moving your eyes, double vision and involuntary eye movements (e.g., a jumpiness from side to side or up and down).

- **BALANCE OR COORDINATION PROBLEMS:**
  this may include tremors, dizziness, feeling uncoordinated or being unsteady on your feet, which can make walking difficult and may lead to falls.

- **MOUTH OR THROAT SYMPTOMS:**
  such as voice changes or difficulty speaking.

- **COGNITIVE SYMPTOMS:**
  such as difficulties with thinking and planning, finding the right word, recognizing people's emotions and memory lapses.

UNDERSTANDING YOUR MS SYMPTOMS

At times you may experience a new symptom or a worsening of an old symptom, which is called an MS relapse (see the next section, MS Relapses). But more commonly, MS symptoms are “background noise” in your daily life – an unwelcome presence that may be a bit better or a bit worse from week to week but you know how to manage them.

But over the course of six months or a year, you may notice that your symptoms are intruding more on your daily life, making tasks more difficult or stopping you from doing the things you need to do. Or you may find that some symptoms have snuck up on you – you have adjusted your life to gradual changes in your day-to-day functioning without fully realizing that the limitations you are facing were not there a year ago.

REPORTING MS SYMPTOMS

It is important to report any new or worsening symptoms you are having to your MS care team and to keep a record of them. Throughout your illness, you will need to inform your MS care team if your symptoms seem to be getting worse, if they are intruding more on your daily life, or if they are preventing you from doing some activities. For example, you may have stopped going to the shopping mall because your occasional bladder symptoms have become more frequent; or your daughter now walks the dog because you find it too difficult; or you are having problems at work because it is getting harder to concentrate or your fatigue is more severe.

MS RELAPSES

MS relapses are new neurological symptoms or a worsening of symptoms you already had before. For example, if a person with arm numbness wakes up to find their eyesight is blurry, this vision impairment would be a new neurological symptom. If a person with mild foot tingling feels the sensation is now numbness or has spread up the leg, this is a worsening of a pre-existing symptom.

The new or worsening symptom must last at least one day for it to be properly called a relapse. A relapse generally represents a flare-up of disease activity. With time, this disease activity will settle down and your level of symptoms may return to what it was before. This is the remission phase and is the reason why the illness is called relapsing-remitting MS.

However, some symptoms may not fully disappear after a relapse and they become the 'new normal' in your daily life. This is more likely to happen if you have a severe relapse or repeated relapses because your body is unable to heal all the damage. Normal aging can also limit your body's ability to repair ongoing tissue damage.

WHEN SYMPTOMS MASQUERADE AS RELAPSES

A relapse occurs when there is a flare-up of disease activity. There are times when a worsening of symptoms is not a true relapse – the symptoms are true, but they are not caused by an inflammatory flare-up. They are caused by an increase in your body temperature. This can happen because you have a fever, an infection, from heat exposure or you are premenstrual. For example, your MS may feel worse during a bout of influenza. Or your symptoms may become more severe if you get overheated from a hot bath, strenuous exercise or being out in the sun. However, this short-term worsening in your symptoms generally does not persist for a full day – you will feel better once you recover from your fever or infection, or after your body has cooled down.

WHEN TO CONTACT YOUR MS CLINIC

If you have a fever or infection, it is best to contact your family doctor for treatment and notify your MS nurse. If you don't have a fever or infection, you have not been overheated, and your symptoms have persisted for more than a day, this is likely to be a relapse and it is best to inform your MS clinic. You should also contact your MS clinic if your symptoms are severe or worrisome. For example, if you lose vision in one eye, are having difficulty walking, experience bowel or bladder incontinence, or you lose the use of one of your hands, it is best not to wait before contacting your MS clinic. Your MS care team needs to stay informed about the problems you are having.

MAGNETIC RESONANCE IMAGING (MRI)

MRI is an imaging method that uses a powerful magnetic field to produce pictures of the brain and spinal cord. A magnetic field identifies differences in tissues, which distinguishes between fatty tissues and areas of higher water content (e.g., due to inflammation). This technology does not expose the body to radiation, unlike other imaging techniques such as X-rays and CT scans.

In MS, different MRI techniques use different types of pictures to show regions of inflammation and damage, which appear as lesions or plaques. The main techniques are called T1-weighted images, in which areas of inflammation or swelling appear as darker lesions; and T2-weighted images, where newer and older areas of inflammation and tissue damage appear as bright spots. So a T2 lesion can be thought of as a photo, and the T1 lesion is the photographic negative.

In some situations, people scheduled for an MRI will receive a contrast agent (usually a substance called gadolinium), which is injected prior to the MRI scan. This produces an image of enhancing T1 lesions, which indicate recent disease activity in the brain.

MRI lesions can develop due to an infection, an injury or different neurological conditions, such as migraine. However, the lesions seen in MS tend to develop in specific regions of the brain, so this characteristic lesion pattern can be used to confirm a diagnosis of MS.

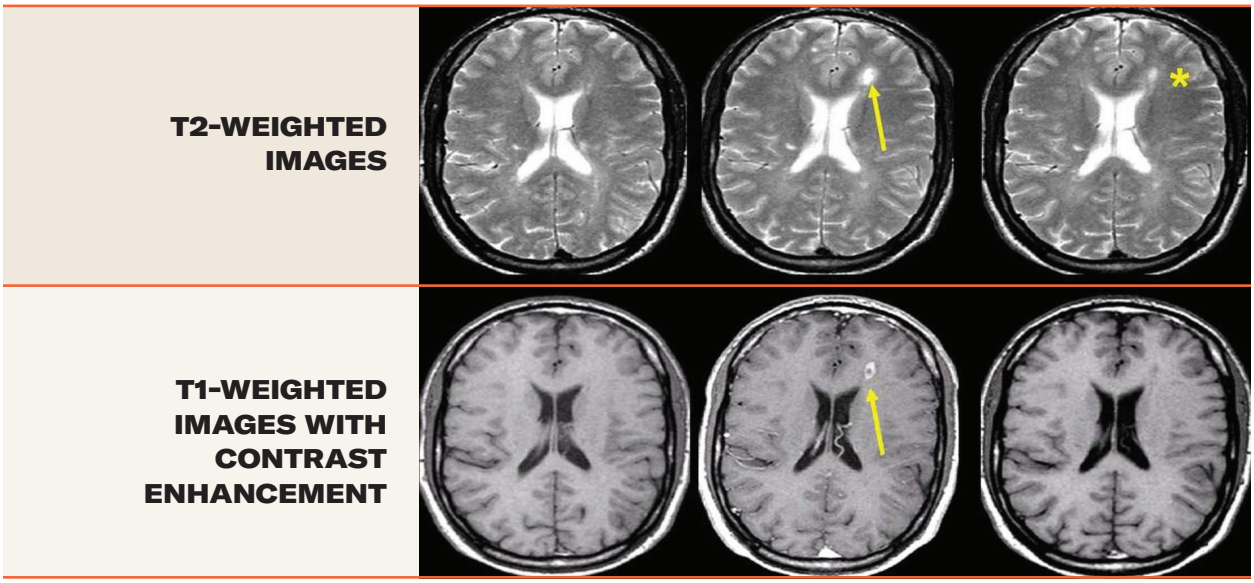
WHAT DO MRIs TELL US ABOUT MS DISEASE ACTIVITY?

As immune cells cross over from the bloodstream into the brain, the resulting inflammation first shows up as an enhancing T1 lesion, which persists for about a month. So an enhancing lesion indicates that there is new disease activity (Figure 1).

T2 lesions indicate areas of inflammation and tissue damage over a longer period of time. A single MRI scan will show new T2 lesions as well as older T2 lesions. A series of MRIs provides an ongoing record of the inflammatory changes in your brain, revealing new lesions, lesions that have healed and some that are slowly expanding in size (Figure 1). The appearance of new lesions and slowly expanding lesions indicates ongoing disease activity and tissue damage. During the course of MS, some T2 lesions can evolve into areas of tissue loss that contribute to worsening disability. The overall burden of lesions contributes to the development of permanent disabilities.

FIGURE 1

HOW MRI LESIONS CHANGE OVER TIME



Arrow indicates a new lesion that has appeared.
Asterisk indicates where a T2 lesion has healed but still leaves a footprint.

From Magnetic resonance monitoring of lesion evolution in multiple sclerosis, by Alex Rovira, Cristina Auger and Juli Alonso. *Ther Adv Neurol Disord* 2013;6:298-310. Sage Journals. DOI: 10.1177/1756285613484079. Used with permission.

The MS symptoms and relapses that you experience occur because of disease activity that may not be visible on an MRI. But MRI lesions can also develop without producing symptoms – they are "silent". So in evaluating your MS, your healthcare team needs to consider the symptoms and relapses you report, as well as the lesions that can be seen on the MRIs that your doctor will obtain periodically throughout your course of illness. Only then can they get a complete picture of the level of disease activity and how well your medication is managing your MS.

WHY DISEASE ACTIVITY MATTERS

The inflammatory disease activity that occurs in MS is an attack on your nervous system. In the first few years of living with MS, your body is able to repair much of the damage that is done. But over the course of your illness, your body is less able to heal itself. This means that symptoms are more likely to persist and worsen, MRI lesions may accumulate and expand in the brain and spinal cord, and the tissue damage may become more extensive. Ongoing disease activity may also contribute to the development of progressive MS – the second phase of the disease process in which healing is impaired and disability becomes progressively worse and irreversible.

An ideal goal in MS is attaining no evidence of disease activity (NEDA). However, this can be difficult to achieve in clinical practice. NEDA is defined as no relapses, no EDSS worsening, and no MRI lesion activity.

TALKING TO YOUR NEUROLOGIST AND MS NURSE

The first step is to ensure that your neurologist, MS nurse and other members of the MS team, such as rehabilitation specialists and family physician, are kept informed of the MS symptoms you are experiencing and if you are having any relapses. When reporting your symptoms and relapses, try to be as specific as you can.

YOUR MS NURSE MAY ASK YOU:

Can you describe the symptoms?

Is this a new symptom or a worsening of an existing one (i.e., a relapse)?

Were the symptoms associated with a fever, infection or your menstrual cycle?

When did the problem start? Did it start quickly, or did it begin slowly and gradually worsened over a few days?

How long did the problem persist?

Have the symptoms caused problems in your daily life?

Have the symptoms interfered with your ability to go to work or school?

Do you feel your day-to-day functioning has gotten worse over the past year?

Everyone's MS is unique, so there may be some trial and error until the right treatment for you is found to manage your MS.

You have an important role to play in this process. Your first task is to take the medication as prescribed by your doctor. The second task is to keep your doctor and MS nurse informed about your symptoms and whether you have experienced any relapses.

Disease activity matters. It provides an indication of how aggressive your MS is, how much damage is being done, and how well your medication is working. Providing your MS team with accurate, up-to-date information about your symptoms and relapses will enable them to develop better strategies to manage your MS throughout the course of your illness.

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