

Clinically Isolated Syndrome (CIS)

Knowledge for the Present,
Hope for the Future



An educational resource from the International Organization of MS Nurses (IOMSN).

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IOMSN

International Organization
of Multiple Sclerosis Nurses
of Multiple Sclerosis Nurses
International Organization

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Message from the International Organization of MS Nurses

Today we can offer a great deal more hope to someone facing a diagnosis of multiple sclerosis (MS) than ever before in the history of this condition. This hope stems from advances in our knowledge about MS and greatly expanded options for treatment.

The time of diagnosis can be scary and uncertain, but it's important to stress that each person's impressions about MS may not match with reality. When the condition is caught early and treated correctly, many people with MS live well and maintain their ability to walk, exercise, work, have families, and enjoy their favorite activities.

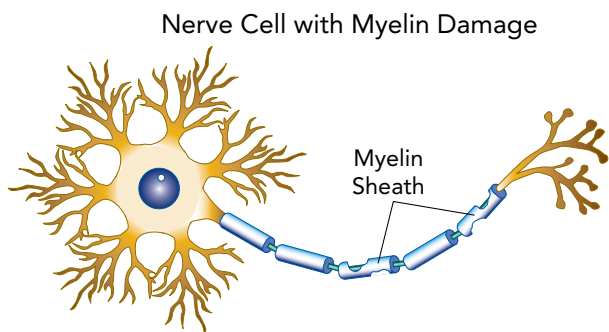
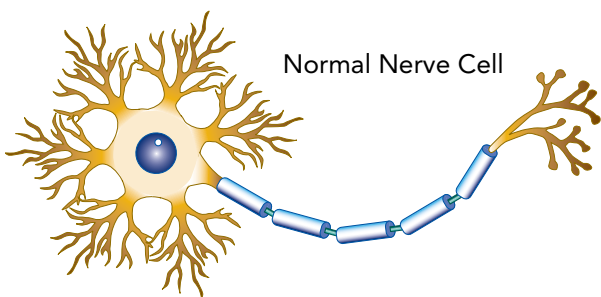
Early diagnosis and treatment are key, as this brochure emphasizes. Partnering with an MS nurse specialist can be a valuable part of this process. Nurses with special training in MS can provide patients with education, guidance, and encouragement as they face the challenges ahead.

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What is MS?

Multiple sclerosis (MS) is a disease in which the nerve tissues in the brain and/or the spinal cord are attacked by immune cells in the body. These immune cells (which include T cells and B cells) are present in everyone. Their normal role is to fight off infections. In people with MS, these cells change the way they function and cross into the nervous system. Once there, they cause inflammation that damages the *myelin* (the protective coating of a nerve cell) and parts of the nerve cell itself.



Researchers have been working for many years to determine why these immune system changes occur in MS. So far, a clear cause has not been found. Several types of drug therapies have been developed that target these wayward immune cells to treat MS.

MS often starts out as the “relapsing-remitting” form. This means that there are episodes or

“relapses” when the person has symptoms, and other times when they recover to normal or near-normal. Some symptoms like odd sensations, fatigue, or weakness may persist between relapses. Over time, if the damage to the nervous system continues, the disease can cause additional disability, such as difficulty walking. Fortunately, today there are effective treatments that dramatically improve the outcome for many patients. If the relapses and nerve damage can be prevented with available medications, many patients with MS can go many years between relapses and have relatively little disability.

What is “clinically isolated syndrome?”

“Clinically isolated syndrome” (CIS) is considered an early stage of MS. People with CIS do not yet have enough symptoms or signs present for a firm diagnosis of MS to be made. However, most people who are told they have CIS go on to develop MS within a few years. Others may not develop MS. Some people have other medical conditions causing symptoms that mimic, or are similar to, those of MS. (In fact, MS has been called the “great imitator” because in its early stages, it often resembles other diseases). We now have more specific tests to diagnose MS, including advanced imaging techniques such as magnetic resonance imaging (MRI). This allows healthcare professionals to make a diagnosis much earlier in the disease process. But unless it can be confirmed, doctors or nurses do not usually say a person definitely has MS until other possibilities can be ruled out. That is why the term CIS is used.

Because CIS represents a “big unknown,” it can be an extremely frustrating and frightening time for the patient and family. It is a critical time



to receive education from experts who know about these conditions and who can offer the necessary support, information, and treatment. MS nurses are healthcare professionals who have special training and experience caring for and counseling patients with CIS and all stages of MS.

How is CIS diagnosed?

Damage to the nerves can build up silently for several years before causing symptoms that lead a person to seek medical help. If a healthcare professional suspects CIS or MS, the person's condition should be assessed via clinical evaluation, MRI, and laboratory tests.

1. Clinical Evaluation: Medical history and physical examination

A neurologist (preferably someone with experience in CIS and MS) will conduct an evaluation. This includes a thorough history to determine what signs and symptoms the person has now or may have had in the past. For example, a person with CIS might have sensations of numb-

ness or tingling in the arms or legs. But this can be caused by many different conditions and would not by itself indicate CIS.

Other early signs include changes in vision. “Optic neuritis”—a sudden onset of decreased vision—is a common sign in CIS. Optic neuritis is caused by pressure on the optic nerve (a nerve sending signals from the brain to the eye), which in turn is caused by inflammation. Optic neuritis may go away on its own but is likely to return if the disease is untreated.

(ERRATA) Please note corrections in definition:

Criteria for a Diagnosis of CIS

Medical experts have developed lists, or *criteria*, that describe the test results and symptoms that are required to make a definite diagnosis of MS. When some (but not all) all of those criteria are present, the condition is called CIS.

CIS is defined as :

- One clinical episode, or “attack,” plus certain magnetic resonance imaging (MRI) results consistent with MS. If a second episode occurs and/or more MRI changes develop, then a diagnosis of MS (“clinically definite MS” or “CDMS”) is made.

RIS (Radiologically Isolated Syndrome) is defined as :

- MRI findings that resemble MS, but without clinical symptoms. This may apply to a person who had an MRI for other reasons (say, to evaluate a headache) with results that looked like MS, but who has never had any corresponding symptoms. This is a relatively new finding and MS experts are studying how to categorize these cases.

2. Magnetic resonance imaging (MRI)

This is one of the most important tests to identify what's happening in CIS. An MRI is a large scanner that uses magnets to capture multiple images of the tissues of the body to form a 3D image. In CIS, these scans are done on the brain and often the spinal cord. A “baseline” MRI (first-time MRI) is done if the person has not had one before. The images obtained from this test, and probably several follow-up tests, will show whether any changes are present that might suggest MS. If enough of these changes are present, a diagnosis of MS is made. If the results of the MRI are normal, show milder changes, or are inconclusive, the condition may be called CIS.

3. Laboratory Evaluation: Tests of blood and spinal fluid

Tests of the blood and possibly spinal fluid are conducted to help rule out other conditions, or to confirm MS or CIS. Some findings from these lab tests might suggest whether a person with CIS has a greater risk of developing MS. These test results cannot be used to make a diagnosis by themselves, but may be considered in combination with your history and neurologic examination.

How often does CIS turn into MS?

The actual risk of CIS turning into or “converting to” MS depends on what combination of symptoms and signs are present. The neurologist or nurse specialist will discuss with the patient his or her health and expected risk of developing MS based on the particular findings from the clinical examination, MRI, and other tests.

The risk of MS is often assessed by the number of areas on the MRI shown to have damage, and the types of changes seen. MRI results can vary from test to test because these images may show temporary changes in the brain, such as inflammation. This is why multiple MRIs are often performed.

Large-scale studies of people with CIS who are not treated aggressively show that approximately 89% will go on to develop MS. We also know from these studies that a person who has had one clinical episode plus MRI changes consistent with MS has a higher risk of developing MS than a person whose MRI appears normal.

Even if MS is ruled out, there could be some other health problem causing the symptoms, which should be investigated further.



**An MRI scan of the brain.
The white spots are MS changes.**

If the diagnosis is CIS, what can be done?

The neurologist or nurse specialist may recommend that people with CIS start treatment with one of a group of medications known as “disease-modifying therapies” or “DMTs.” Medica-

tions like steroids can be used temporarily to reduce inflammation to try to improve symptoms.

Other steps will include regular follow-up, preferably at an MS center or with a neurologist specializing in MS, and repeat MRI exams, usually within three to six months.

Why is it recommended that people with CIS take medications for MS when they haven't actually been diagnosed with MS?

DMTs for MS are mainly effective at preventing future damage to the nerve tissues in the brain and spinal cord. We don't know whether they are capable of repairing any existing damage to the brain cells. We do know that these drugs work best in the earlier stages of the disease and are less effective once MS has progressed further.

What evidence shows that these treatments work in CIS?

Several large clinical studies have been conducted in over 1,100 people with CIS. These studies show that treating CIS with DMTs substantially extends the time until people have another relapse. Treatment can delay the next relapse by as much as five years. In contrast, one



study showed that over 50% of people with CIS who were *not* treated had a relapse within six months, leading to a definite diagnosis of MS.

DMTs also prevent changes on the MRI that represent damage to the nerve cells and brain tissues. The longer this damage can be delayed or prevented, the more likely that nervous system functioning will be maintained. Thus, treating CIS is really staving off future damage to the body. This might be compared to the way that treating cancer early with chemotherapy prevents the cancer from spreading in the body.

As we discussed earlier, CIS has not been defined as relapsing MS. If a person has a second relapse or attack, the diagnosis of MS is confirmed.

Four DMTs are currently approved by the Food & Drug Administration (FDA) for reducing the chance of relapse in patients with CIS:

Interferon beta-1a (intramuscular)	Avonex [®]
Interferon beta-1b	Betaseron [®] , Extavia [®]
Glatiramer acetate	Copaxone [®]

Each of these therapies has been used and studied in patients with MS for many years and each has been shown to be safe for consistent



use over long periods of time. Right now, these DMTs represent the best available way for people with CIS to delay relapses or attacks, reduce the number and severity of relapses, and prevent long-term damage to the nervous system.

Why should an injectable drug treatment be started?

MS is not a benign disease, and its management is not simple. Thankfully, MS *is* treatable. Many people living with MS today are leading full, productive, active lives thanks to the availability

Managing CIS

DO:

- Get a second opinion—get evaluated at a specialized MS center if you have not already done so.
- Start your own personal record of all your MRI results, copies of medical tests, lists of practitioners seen and dates, etc. This will help you and your care team if you are evaluated by different specialists or at multiple clinics or labs.
- Get your health insurance in order and make sure you understand your coverage.
- Develop healthy lifestyle habits, from exercise and stretching to good sleep habits and healthy eating. All of these will make you feel better whether you do or do not have a neurologic condition. If you're in doubt about how to do this, ask your healthcare provider for referrals or find a health professional to help you select a diet and supplements that are right for you.

of modern treatments. Experts believe that treating MS as early as possible—especially during CIS—is the best way to prevent permanent damage and sustain the quality of life.

There is much more hope on the horizon, too. Several experimental therapies are being tested now to determine whether they are safe and effective for MS. In particular, these agents may offer hope for people who do not respond well or cannot tolerate the currently available therapies. In addition, advanced research is ongoing

DON'T:

- Rely on the Internet! Many of us turn to the Internet for health information despite knowing that what is “out there” online can be misleading and sometimes flat-out wrong. Some people who post on MS discussion boards may have long-standing disease or multiple health problems. Your condition and the course of your health may not be the same as theirs.
- Try to become an MS expert overnight. Avoid overwhelming yourself by trying to learn everything possible about this disease. Don't jump to conclusions about your own prognosis. Instead, take some time to talk to a neurologist or MS nurse specialist about what *does* apply to you and what you might expect in your own situation. Remember: MS is a condition that changes and must be evaluated continuously.

to learn more about the processes involved in MS at the cellular level, in the hopes of finding ways to better treat or even prevent MS.

What is the best way to manage the period of “not knowing”?

For many people, being diagnosed with CIS is like being in limbo. The uncertainty of this situation can cause much fear and stress. See the Do's and Don'ts box on pages 10-11 for some practical tips to help you through this time.

If you are going to connect with someone else who has MS, look for someone who can be a positive role model. Peer support services help you find people with MS who have handled this condition on their own terms. You can find out about these services on the websites listed on pages 14-15.

Conclusion

When a person is faced with the possibility of a disease like MS, it's normal to experience a variety of emotions. People commonly think they can delay treatment until they experience additional symptoms or get worse. Taking a “wait and see” approach with CIS is no longer advised. The evidence clearly shows that treating CIS early is the best way to stay healthy and take control of this disease. New knowledge that is advancing our skills and a supportive health-care team equals hope in meeting the challenges of CIS.

NOTES

I need to talk to my provider about:

[illegible]

Pharmaceutical Industry-Sponsored Programs

Avonex® Services (Avonex®* and Tysabri®)

Tel: 800-456-2255 (M-F 8:30 am - 8:00 pm ET)

Websites: www.avonex.com, www.tysabri.com

Betaplus™ (Betaseron®*)

Tel: 800-788-1467 (M-F 8:00 am - 8:00 pm ET)

Website: <http://betaseron.com/patients/betaplus/>

Extavia® Patient Services (Extavia®*)

Tel: 866-925-2333

Website: www.extavia.com

MS LifeLines (Rebif® and Novantrone®)

Tel: 877-447-3243 (M-F 8:00 am - 8:00 pm ET)

Website: www.mslifelines.com

Shared Solutions (Copaxone®*)

Tel: 800-887-8100 (M-F 8:00 am - 8:00 pm CT)

Website: www.copaxone.com/supportservices/default.aspx

Multiple Sclerosis Organizations

Consortium of Multiple Sclerosis Centers

359 Main Street, Suite A

Hackensack, NJ 07601

Tel: 201-487-1050

Website: www.mscares.org

International Organization of Multiple Sclerosis Nurses

359 Main Street, Suite A

Hackensack, NJ 07601

Tel: 201-487-1050

Website: www.iomsn.org

Multiple Sclerosis Association of America

706 Haddonfield Road

Cherry Hill, NJ 08002

Tel: 800-532-7667

Website: www.msassociation.org

Multiple Sclerosis Foundation

6350 N Andrews Avenue

Fort Lauderdale, FL 33309

Tel: 888-MSFOCUS (888-673-6287)

Website: www.msfocus.org

Multiple Sclerosis Society of Canada

Tel: 800-268-7582

Website: www.mssociety.ca

National Multiple Sclerosis Society

733 Third Avenue, 3rd Floor

New York, NY 10017

Tel: 800-FIGHT-MS (800-344-4867)

Website: www.nationalmssociety.org

Other Patient Resources

Can Do Multiple Sclerosis™

Tel: 800-367-3101

Website: www.mscando.org

MS Perspectives (a patient publication)

Website: www.msperspectives.com

MS Views & News

Website: www.msviewsandnews.org

MS World

Website: www.msworld.org

*The four highlighted drugs above are approved by the FDA for use in people with CIS as well as relapsing forms of MS.

The mission of the International Organization of Multiple Sclerosis Nurses (IOMSN) is the establishment and perpetuation of a specialized branch of nursing in multiple sclerosis; to establish standards of nursing care in multiple sclerosis; to support multiple sclerosis nursing research; and to educate the healthcare community about multiple sclerosis and disseminate this knowledge throughout the world.

The ultimate goal of the IOMSN is to improve the lives of all those persons affected by multiple sclerosis through the provision of appropriate health-care services.

Additional copies of this pamphlet may be obtained by contacting the IOMSN at www.iomsn.org or via email at info@iomsn.org.



