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**MULTIPLE
SCLEROSIS
AND
PAIN**

2ND EDITION

ms.

Multiple Sclerosis Society of New Zealand

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INTRODUCTION

Half of all people with MS will experience pain from time to time because of the condition. Fortunately for most, the pain is usually mild. But, for a small number, pain is a more troublesome and ongoing symptom that may need specialised assessment and treatment.

The severity or frequency of pain varies from person to person. It cannot be predicted by a person's age, gender, or type of MS. However, the longer someone has had MS, the more likely they are to experience pain as one of their symptoms.

Pain may be directly related to the disease itself (e.g. pain associated with nerve damage), or it may develop because of other MS problems (e.g. pain caused by painful muscle contractions and stiffened joints). Fortunately, most pain in MS can be treated.

This booklet outlines some of the common types of pain in Multiple Sclerosis and describes the range of treatments available.

HOW PAIN HAPPENS

There are nerve endings sensitive to pain all over the body that sound an alarm to the brain when something is harming or about to harm it, such as a hot fire or a pulled muscle. The pain signals are generated by nerve cells in muscle and skin and move through the body to the spinal cord and into the brain for processing.

The main type of pain in MS mimics these warning signals and usually comes from staying in one position for too long, from muscle spasms or from physical stress caused by compensating for weakness and poor coordination. This is musculoskeletal pain.

In contrast, pain may also occur because of injury to the nervous system itself. This pain may arise spontaneously rather than in response to a specific action and generally serves no purpose. Pain caused by nerve damage can range from a mild prickling to severe burning or aching and usually requires different treatment from musculoskeletal pain.

In some chronic pain conditions, the constant barrage of pain signals may overwhelm the central nervous system so much that normal sensations such as the stroke of a hand can trigger pain.

Aside from physical issues, it is extremely important to recognise the emotional effects of experiencing pain and to develop healthy coping strategies.

To that end, it can be useful to:

- ➔ Learn relaxation and meditation skills.
- ➔ Concentrate on positive thoughts and activities.
- ➔ Talk to a counsellor.
- ➔ Seek assistance from an MS Society Field Worker.
- ➔ Contact a support group for people with chronic pain.

Some practical suggestions for managing pain include:

- ➔ Exercising gently and regularly, within your limits.
- ➔ Modifying your environment (e.g. comfortable bedding).
- ➔ Considering equipment that may prevent pain from being triggered (e.g. a gripping stick to avoid having to reach).
- ➔ Treating flare-ups as they occur - delay can cause problems.
- ➔ Seeing a physiotherapist regularly.

Where pain is particularly troublesome, your GP may refer you to a pain clinic at the local hospital, where a specialist will work with you to develop strategies for managing the pain.

Non-medical approaches to pain management include massage, hydrotherapy, acupuncture and reflexology. However, these activities must be discussed with your doctor beforehand.

It is crucial to note that not all pain experienced by people with MS is due to the condition. Either way, if you are experiencing any significant pain you **MUST** see your doctor or neurologist to receive an accurate diagnosis and effective treatment.

Common MS-related pain issues are listed in the next sections.

PAIN FROM NERVE DAMAGE

Damage to the nervous system can produce pain that feels like tingling or burning. The pain can be very strong, but is usually intermittent.

The most common locations for this type of pain are the face, neck and torso.

TRIGEMINAL NEURALGIA

Description

Excruciating, sharp, shock-like pain in one side of the face, lasting seconds to minutes and often repeated; may be triggered by speaking or a touch. Usually settles spontaneously by itself over several weeks.

Usual medications

Carbamazepine, phenytoin and baclofen. Gabapentin may also help.

LHERMITTE'S SIGN/SYMPATOM

Description

A brief, stabbing, shock-like sensation that runs from the back of the head down the spine, brought on by bending the neck forward. It is not always painful.

Usual medications

Carbamazepine or phenytoin.

Other treatments

A soft collar may limit neck movement. Most often this disorder disappears spontaneously and medical treatment is not necessary.

TONIC SPASMS

Description

Sudden and painful muscle contractions, producing stiffness of the whole limb, which can last up to two minutes.

Usual medications

Carbamazepine, phenytoin, baclofen and clonazepam.

Note: The MS Society produces a booklet on this topic, called MS and Spasticity. Contact us if you would like a copy (contact details are on the back page of this booklet).

DYSAESTHETIC PAIN IN LIMBS AND TRUNK

Description

Persistent burning, tingling, tightness, or aching; may be worse at night and after exercise, may be aggravated by temperature and weather.

Usual medications

Nortriptyline and amitriptyline. Gabapentin, tegretol and epilim may also be useful.

Other treatments

Application of cold, pressure stockings, capsaicin ointment.

SECONDARY PAIN FROM MS

Mostly, pain in MS is due to immobility or poor posture, rather than directly related to damage to the nervous system. In particular, using the same posture repeatedly with mobility aids (e.g. a frame or wheelchair) will put stress on the body, which can cause pain. A physiotherapist can provide useful guidance in this area.

The non-medical approaches mentioned in the previous section of this booklet are suitable for this type of pain, but it is crucial to consult your doctor beforehand.

MUSCULOSKELETAL PAIN

Description

Stiff joints and muscle contractures, caused by the physical stress of immobility. It can affect the neck, the back or limb joints.

Usual medications

Ibuprofen, diclofenac and naproxen.

Other treatments

Stretching exercises, posture & gait examination, orthotics, exercise (especially swimming), position changes, support and cushioning, application of heat and cold.

NERVE PRESSURE PAIN

Description

Pain caused by pressure on the nerves from immobility or poor posture. This can include sciatic nerve pain from pressure on the back of the leg and ulnar nerve pain from pressure on the elbow.

Usual treatment

Correct seating is important, but elevation of the legs will usually relieve pressure pain.

BACK PAIN

Description

This can be caused by muscle weakness, abnormal posture, spasticity and spasm. It may also occur as a result of osteoporosis or MS lesions in the spinal cord.

Usual treatment

Evaluation to pinpoint the source of the pain is essential, as treatments differ widely. It is also important to note that back pain is not always related to MS.

PAIN FROM MS SYMPTOMS AND TREATMENTS

Description

Some MS symptoms can cause pain in addition to the symptom itself, such as pressure sores, urinary retention and infections. A particular example is pain due to Optic Neuritis—an MS symptom that occurs when the optic nerve is stretched or inflamed. This is treated with methylprednisolone, ibuprofen, diclofenac or naproxen.

People with MS can also experience pain as a result of treatment for the condition. Two examples include injection-site reactions and steroid-induced osteoporosis.

Usual treatment

It is very important to discuss each particular problem with your healthcare provider. Fortunately, fixing the initial problem or changing treatment options often eliminates the pain.

FINAL THOUGHTS

It is important to get pain treated. You should discuss where and how much pain you have with your healthcare provider. Your own description of the pain is the most important aspect of pain assessment.

To improve your descriptions, keep a pain diary and watch for pain triggers. Notice things that make your pain worse such as certain movements, fatigue, or worsening of other MS symptoms. Rate your pain on a scale of zero to 10 (with zero = no pain and 10 = worst pain). As you rate the pain, note any activities, time of day, where you are and whom you are with. Describe the pain (sharp, achy, stinging, etc.) and what you did about it.

If you are prescribed medications, learn their names and any side effects. Ask about the best time to take each one and what it is expected to do for you.

Work with your doctor to experiment with a variety of reliable treatments, including non-medical approaches if these are appropriate.

The most important thing about managing pain is to be well informed about your choices and monitored closely for potential side effects.

Be an advocate in your own pain management.

SOURCES OF SUPPORT AND INFORMATION

THE MS SOCIETY OF NEW ZEALAND

We can put you in contact with a regional Field Worker. They arrange social groups, exercise classes, support meetings and referrals within their regions. Some people with MS find support groups helpful as an occasion where they can share their experiences and learn how others deal with MS. Contact details for your nearest regional society are located over the page.

INTERNET RESOURCES

The Internet provides a great deal of information about MS, but the quality and accuracy of the information can vary. Some useful websites are:

MS Societies

MS Society of New Zealand	www.msnz.org.nz
MS International Federation	www.msif.org
Australia	www.mssociety.com.au
United Kingdom	www.mssociety.org.uk
United States	www.nmss.org

Disability

Weka: What Everyone Keeps Asking—about disability

website www.weka.net.nz

phone 0800 17 1981

CONTACT DETAILS

THE MS SOCIETY OF NZ

We are available to help you with your queries and give you information and guidance.

MSNZ

PO Box 2627 Wellington 6140 NEW ZEALAND

Phone 0800 MS LINE or 0800 675 463

OR 04 499 4677

Email info@msnz.org.nz

Website www.msnz.org.nz

REGIONAL MS SOCIETIES

Northland	09 438 3945	Manawatu	06 357 3188
Auckland & North Shore	09 845 5921	Wellington	04 388 8127
Waikato	07 834 4740	Marlborough	03 578 4058
Bay of Plenty	07 571 6898	Nelson	03 544 6386
Rotorua	07 346 1830	West Coast	03 768 7007
Gisborne	06 868 8842	Canterbury	03 366 2857
Hawkes Bay	06 843 5002	South Canterbury	03 684 7834
Taranaki	06 751 2330	Otago	03 455 5894
Wanganui	06 345 2336	Southland	03 218 3975



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