Managing Pain

For People Living with MS





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Published by: Multiple Sclerosis Limited ABN: 66 004 942 287

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MS Limited strives for a world without multiple sclerosis through quality research and for service excellence to people with multiple sclerosis and their carers.

Acknowledgements

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MS Limited – ACT/NSW/TAS/VIC gratefully acknowledges the generous grant received from The Marian & EH Flack Charitable Trust for the development of this resource.

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ISBN: 978-0-9578090-3-1

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Introduction

With approximately 60 percent of people with multiple sclerosis (MS) experiencing pain, this booklet has been developed to provide people with MS, their families and carers with practical information on managing MS-related pain.

Managing Pain for People Living with MS provides:

- answers to commonly-asked questions about pain;
- information on medications used to treat MS-related pain;
- suggestions for working more effectively with your healthcare team; and
- practical strategies to self-manage MS-related pain.

Managing Pain for People Living with MS highlights the importance of developing a personal pain management plan. The information provided culminates in a template (on page 13), which enables readers to apply the knowledge they have learned to start developing their own pain management plan.



Thank you for this booklet! The information has helped me to better understand my pain and how to manage it

Why do people with MS experience pain?

Pain is a common symptom of MS. Approximately 60 percent of people with MS experience pain that troubles them or interferes with their day-today activities¹. For many, this pain is constant but varies in its severity.

MS-related pain comes from two main sources in the body:

- Neurological. Also referred to as neurogenic or central pain, this is caused by MS-related damage to the brain, spinal cord and nerves. Messages sent along damaged nerves can be interrupted or confused, resulting in pain. Sometimes, however, the nerves will mistakenly send pain messages to the brain. Neurological pain can feel unusual – tingling, pins and needles, tight bands, burning and stabbing are common ways to describe this pain.
- 2. Musculoskeletal. Also referred to as nociceptive pain, this is caused by damage or changes to the body's bones, muscles and soft tissues. Examples include pain due to muscle spasms and pain as a result of inactivity or altered posture.

People with MS can also experience pain that is not related to their MS. Examples of this may be lower back pain from an injury received while lifting a heavy box, foot pain caused by diabetes or pain from a broken bone.

There is also a difference between chronic and acute pain.

Chronic pain (also called persistent pain) is any pain that lasts for more than three months and can go on for years. This sort of pain usually doesn't respond very well to regular medication and needs a more complex management plan. Chronic pain is the most common type of pain affecting people with MS.

Acute pain lasts for a shorter time and is usually related to injury or short-term illness (for example, a broken bone or gout).

While it can be difficult to establish which type of pain you are experiencing, it is important to consult your general practitioner (GP) and neurologist about this and any other symptoms you are experiencing.

I used to worry that I had more than MS but now I know that this is what causes the tight bands and tingling

KEY POINTS:

- Pain is a common symptom of MS.
- About 60 percent of people with MS experience pain.
- MS-related pain can come from:
 - 1. neurological sources (MS-related damage to the brain, spinal cord and nerves); or
 - 2. musculoskeletal sources (damage or changes in bones, muscles and soft tissues).

1. Kahn F and Pallant J. Chronic Pain in Multiple Sclerosis: Characteristics and impact on quality of life in an Australian community cohort. J Pain 2007;8(8):614-623.

Where can I get help for pain?



It can be difficult to know what to do the first time you experience pain. Your general practitioner (GP) can help you to manage pain, especially if it is sudden or severe. GPs can also help with the day-to-day management of your MS-related pain, and can establish if the pain is caused by something other than MS (such as a back injury or other medical problem).

We also recommend talking to your neurologist about any new pain, changes in your pain or unusual sensations you are experiencing. This will help your neurologist to provide you with good advice about pain management.

Some people find it difficult to talk to their doctors about pain – some worry about taking up too much of their doctor's time, while others aren't sure what they should tell their doctor. Remember, your doctor is there to help you.

Be prepared

When visiting your doctor it is helpful to be prepared. Before your appointment, write down

the things you would like to tell your doctor and the questions you would like to ask. This will help you to remember them and can also help you to feel more at ease. It is also helpful to write down the answers your doctor gives (while you're in their office). This will ensure you have understood your doctor and will help you to remember what they have said.

Alternatively, it may be helpful to take a family member, carer or friend with you who can help with writing down and recalling the information.

As a guide, below are some key things to discuss with your doctor, as well as some questions you may need to ask them.

Key things to tell your doctor:

- Detailed information about your pain (or any new symptom), including:
 - where you feel the pain (e.g. head, neck, arms, left leg);
 - when you feel the pain (e.g. day/night, when walking);

Where can I get help for pain? (cont.)

- how the pain feels (e.g. burning, aching, tingling, stabbing);
- if anything changes the pain (e.g. worse in hot weather, improves with ice, feels different after exercise);
- how the pain affects you (e.g. makes it hard to get to sleep, means you walk less, stops you doing a favourite activity); and
- what you have done to attempt to relieve the pain (e.g. taking paracetamol, stretching, physiotherapy, rest).
- If your pain has changed, worsened or gone away.
- How you are managing all of your MS symptoms, including pain.
- Any significant changes you have made in your life, such as changing jobs, starting exercise for the first time, changing your diet, getting married, being diagnosed with another medical condition or changing your work arrangements.

Pain clinics

If your doctor thinks you need specialised help with pain they may recommend you visit a pain clinic. At a pain clinic you will be seen by a range of health professionals, such as a pain specialist (doctor), physiotherapist, clinical psychologist or psychiatrist, nurse, occupational therapist, social worker and rehabilitation specialist.

For more information on pain clinics, or to find one close to you, visit the Australian Pain Society website at www.apsoc.org.au

Overall, it is important to have a good relationship with your GP and neurologist. If you don't feel satisfied with the outcomes of your visit to the doctor, we recommend you seek a second opinion.



Key questions to ask your doctor about pain:

- How can I tell if a particular medication or pain management strategy is working?
- Is there anything I can do to better manage my pain?
- Is there anyone else who can help me better manage my pain?

(More specific questions relating to medications can be found on page 8.)

- Your general practitioner should be your first stop for help with pain.
- Your neurologist can also be helpful.
- When you visit your doctor, be prepared with a list of things to tell them and a list of questions to ask. Write down the answers and/or take someone with you.
- Pain clinics can be helpful if you need further assistance with pain management.
- Don't be afraid to seek a second opinion.

How can families and carers help?

It can be difficult to know how to help someone when they are in pain. You don't want to completely take over and leave them with nothing to do, but you also don't want to see them struggling to do things you could easily help with. Finding the right balance can be challenging and usually requires good communication and practice.

It is helpful to understand how pain is caused in people with MS. It can be particularly helpful to explain pain to children so they understand what is happening. The information in this booklet is a great starting point and more information can be found in the resources listed on page 17.

What signs should I look out for?

Pain is an invisible symptom of MS. It can be hard to tell if someone is in pain so it is important to ask them directly. If a person with MS finds it difficult to tell you they are in pain, it can be helpful to look out for the following signs:

- wincing, awkward movements, doing usual tasks differently;
- being less talkative or less involved in usual activities;

Do:

- ask if there is anything you can do to help;
- encourage them to be as active as possible;
- learn what they do to manage their pain;
- help them work out what questions to ask their doctor or health professional; and
- stick to 'normal' topics of conversation.

being grumpy, snappy or more emotional than usual; and/or

moaning or groaning sounds.

What questions should I ask?

When someone is living with pain, communication is very important. Sit down and talk with them about their pain – ask questions that will help you to understand their pain, learn what makes their pain better or worse, and find out if there is anything you can do to help.

Questions you may like to ask include:

- What makes your pain better or worse?
- What medication do you take for your pain?
- How can I be more helpful?
- What am I doing that isn't helpful?
- How can I support you in managing your pain?

How can I help someone in pain?

Help is very important however, when someone is living with pain, some things are more helpful than others. The table below outlines some basic 'dos' and 'don'ts' for helping someone who is in pain.

Don't:

- automatically take over all of their jobs;
- tell them to rest all of the time;
- try to manage their pain for them;
- do all the talking for them;
- talk about pain all the time; or
- totally ignore the pain.

It's important to include your family. My wife is my greatest support

- Families and carers should have a basic understanding of MS-related pain.
- Talk with your family member or friend about their pain so you can understand what they are experiencing.
- Work out the best way to help them by communicating and working it out together.
 Don't guess.

What medications are used to treat MS-related pain?

There are many different types of medication used to treat MS-related pain. The type of medication your doctor recommends will usually depend on the source of your pain. The table below shows the different medication groups and provides examples of each.

Medication Group	Examples	Overtiens to ack your destay shout
Anti-convulsants	Epilim Gabapentin Pre-Gabalin Carbamazepine	 Questions to ask your doctor about medication: When is the best time to take this medication (e.g. regularly or only when the pain occurs)? Am I taking my medication in the most
Anti-depressants	Endep Tofranil	 effective way? What side-effects can occur with this medication and what should I do if I
Simple analgesics (also called non-opiods)	Paracetamol Ibuprofen	 experience these side-effects? Will this medication react with other medications I am taking? Is this a long, or short term treatment?
Strong analgesics (also called opiods)	Oxycontin Tramadol	 Is this a long- or short-term treatment? When will my medication be reviewed? What should I do if I would like to stop this medication?
Anti-spasmodics	Baclofen Valium	

If your pain is from neurological sources (MS-related damage to the brain, spinal cord and nerves) your doctor will most likely suggest taking an anti-convulsant medication. These medications affect the way messages are sent along nerves. Pain from neurological sources can also be eased by low doses of anti-depressant medications.

If your pain is from musculoskeletal sources (damage or changes in bones, muscles and soft tissues), your doctor may recommend a simple or strong analgesic, as these specifically ease pain that is related to the body's soft tissues.

Alternatively, your doctor may suggest an anti-spasmodic medication if your pain is likely to be caused by muscle spasticity or spasm.

While most people obtain some relief from the types of medication discussed above, it is important to note that, in most cases, MS-related pain is caused by a range of factors and medication alone cannot completely relieve the pain.

While some people believe marijuana can provide a certain degree of pain relief, we do

not recommend its use – marijuana is illegal; can seriously affect thinking, memory and concentration; and is thought to worsen MS-related changes in the brain.

While cannabinoids (active components of the drugs found in marijuana) have been approved for use in some countries, they are not widely available or commonly used in Australia.

Overall, it is important to talk with your doctor regularly about your pain management plan, including medication and any side-effects.

- Many different types of medication can help treat MS-related pain, including anti-convulsants, anti-depressants, simple analgesics, strong analgesics and anti-spasmodics.
- Medication rarely relieves MS-related pain completely.
- Talk to your doctor about any questions or concerns you have about medication.

How can physical activity and exercise help with pain?



In order to live an active and fulfilling life, people with ongoing pain need to ensure they remain as physically active as possible.

Some people find that certain activities can make their pain worse. As a result, they tend to rest more and are less active.

While rest can help relieve pain, long periods of rest or inactivity can lead to physical deconditioning – the gradual loss of strength and fitness that comes from reduced activity levels. As the body loses strength and fitness it is more difficult to do normal activities. It may even become painful to do normal activities that were previously not painful. This could lead to difficulty participating in day-to-day activities.

Maintaining fitness and strength does not mean you have to join a gym. Just keeping up with usual daily activities can help you to avoid deconditioning. If doing this is already difficult it can be helpful to use a strategy called pacing. Pacing involves breaking large tasks into smaller chunks and taking regular, short breaks before you overdo it.

For example, if you haven't been able to wash all the dishes because the pain gets too severe, you may do the following:

- **1.** Wash the glasses.
- **2.** Take a five-minute break.
- 3. Wash the plates and bowls.
- 4. Take another five-minute break.
- **5.** Go back to the sink and finish the job.

During breaks you may need to lie down or you may be able to do a different activity, such as reading the newspaper or checking your email.

Pacing may seem frustrating at times because you might feel that it takes a long time to get things done. However, over time pacing will help you to maintain a regular level of daily activity and can help minimise your pain and the need to take long rests. People with MS participating in a Heartmoves for MS class.



Exercise and pain management

Exercise is an essential part of managing your MS as it can help with balance, mobility and fatigue, and can even improve your mood.

People who exercise regularly tend to be able to cope better with the demands of daily activity. Exercise can even provide pain relief to some, and is therefore an essential part of any pain management plan.

It doesn't matter what you do, as long as it is regular exercise. You could try participating in an exercise class, doing exercises at home, walking, going to the gym, or aquatic exercise (like swimming or hydrotherapy). There are a lot of different ways to exercise; some people prefer to exercise alone while others prefer a group program. It's important to find a way to exercise that suits you. Physiotherapists and exercise physiologists can help you establish the best exercise regime to suit your ability and needs. Call 1800 042 138 for more information on the services provided by the MS Australia centre in your state, or to find an MS-specific exercise class near you.

Physiotherapists and exercise physiologists can also be found by visiting the websites listed in our resources list on page 17. In some situations, your GP can provide you with a referral that will allow you to receive a Medicare rebate for seeing a physiotherapist or exercise physiologist. It would be a good idea to talk to your GP about this at your next visit.

- Deconditioning is the gradual loss of strength and fitness that comes from reduced activity levels. This can increase the severity of pain.
- Regular physical activity and exercise can reverse deconditioning and help ease pain.
- For help with physical activity and pain, speak with a physiotherapist or exercise physiologist.

What else can I do to manage my pain?

For some people, medication and exercise are not enough to effectively manage their pain. Combining these with different lifestyle changes and strategies can help to reduce the impact of pain on your day-to-day life.

Below are some examples to help get you started. These strategies work best if you practise them over a period of time.

Slow breathing and relaxation

It is easy to become tense and stressed when you are in pain. However, symptoms of stress, such as tight shoulder muscles or an increased breathing rate can actually make your pain worse.

To help reduce tension and stress, set aside some time to practise slow breathing or other relaxation exercises. Try this exercise:

- 1. Sit or lie comfortably.
- **2.** Breathe in slowly for three to four seconds, filling your lungs all the way. Your shoulders should stay still and your abdomen will push out as you breathe in.

- **3.** Slowly breathe out, taking three to four seconds to let all the air escape.
- **4.** Repeat for at least 10 breaths, or as long as you need to feel more relaxed.

Listening to music may also help you to relax, as can other relaxation or breathing exercises, such as meditation and yoga.

Goal setting

While pain can be disruptive, setting realistic goals and planning can help you to achieve the things you want to do.

The following steps can help you to set and achieve your goals:

- **1. Set a goal:** What do you want to achieve and by when?
- 2. Be specific: For example, instead of 'I want to exercise', say 'I will go to an exercise class at my local gym every Tuesday afternoon for the next three months'.
- **3. Take action:** List all the steps you need to take to achieve this goal and, again, be specific



(e.g. join the gym, organise babysitting for Tuesday afternoons, pack a bag, drive to the gym, attend the class).

- 4. Start working on your goal.
- **5. Reward yourself:** When you have achieved your goal, give yourself a small reward, such as a trip to the movies or a massage.
- 6. Set another goal and stay motivated!

Challenge your thinking

When you experience pain, it is easy to look at the negative side of things. However, while thinking and saying things like 'Pain stops me doing that' or 'This really, really hurts' may be true, focusing on the negative can cause you to feel down on yourself, cranky, grumpy or worried.

See if you can challenge your unhelpful thinking. Ask yourself these questions:

Is my thinking helpful?

- Is there a different way of looking at this situation?
- What else could I say to myself?
- What advice would I give a good friend in this situation?

Answering these questions won't change your situation or take away your pain, but it might help you feel more positive about life, and you may be able to better manage your pain.

For more information on these and other strategies to help manage pain, speak with your healthcare team or read *Manage Your Pain* by Dr Michael Nicholas et al.

A referral from your GP to a clinical psychologist or other health professional may allow you to access a Medicare rebate. Private health insurance rebates may also be available.



- Certain lifestyle changes and strategies can help to reduce the impact of pain on your day-to-day life.
- Slow breathing, relaxation, goal setting and challenging your thinking are examples of these strategies.
- For more information on different pain management strategies, speak to a health professional or refer to the additional resources on page 17.

My Pain Management Plan

If you are troubled by pain, it is important to have a plan to manage it effectively. The steps below will help you to write your own pain management plan. Use this as a 'work in progress'. Create your plan and test it out. If you need to make any changes, adjust your plan and test it out again. Keep doing this until you are happy with your plan and you are managing your pain well.

STEP 1: WHO CAN HELP?

Who can help with my pain management? (e.g., neurologist, physiotherapist, clinical psychologist, GP, family/friends)

Name	Phone number	How they can help
-		

Questions to ask my doctor:	Answers:
•	•
•	•
•	•
•	•
•	•

STEP 2: STRATEGIES TO MANAGE MY PAIN

Medication I take for pain:

Name	Dose	Time	Reason	Due for Review
				•

My Pain Management Plan

Who can help with medication? (e.g. prescribing doctor, pharmacist)

Name	Phone number	Comments

My exercise plan:

Activity	Day	Time	Location

Who can help with exercise? (e.g. physiotherapist, exercise physiologist, exercise class instructor)

Name	Phone number	Comments

Reminders about pacing:

Activities I should pace:	What to do in my break:
•	•
•	•
•	•
•	•
•	•

Who can help with pacing? (e.g. family, friends, work colleagues)

Name	How they can help

What are my goals?

What do you want to achieve and by when?	Steps to take:
•	•
	•
	•
	•
	Reward:
•	•
	•
	•
	•
	Reward:
•	•
	•
	•
	•
	Reward:

What do I need to do to relax?

Activity	When	Where	How often

Positive things to say to myself:

•	
•	
•	
•	
	······

My Pain Management Plan

STEP 3: FLARE-UP PLAN

What are the early warning signs that my pain might be getting worse?

What should I do immediately?

•
•
•
•

What should I do for the next few hours?

•
•
•
•
•

What should I do for the next few days?

For more information or assistance with developing your pain management plan, speak with your healthcare team, call the MS Connect on 1800 042 138 and/or refer to the additional resources list on page 17.

Further reading and resources

Accessing health professionals and services:

MS - www.ms.org.au

MS provides a range of services to people with MS, including specialist health care and advice, education programs and resources, and access to physical activity groups. Visit the website above to locate your local MS centre, or phone 1800 042 138.

- Australian Association for Exercise and Sports Science www.aaess.com.au
 Visit the website to locate an exercise physiologist near you.
- Australian Pain Society www.apsoc.org.au
 Provides information on pain clinics and services for people with pain in Australia.
- Australian Physiotherapy Association www.physiotherapy.asn.au
 Visit the website to find a physiotherapist near you.
- Australian Psychological Society www.psychology.org.au
 Visit the website to find a clinical psychologist near you.
- Chronic Pain Australia www.chronicpainaustralia.org
 A community advocacy and support organisation, committed to helping people live with chronic pain.

Additional resources to learn more about pain:

- MS In Focus: Pain in MS Multiple Sclerosis International Federation http://www.msif.org/docs/MSinFocusIssue10EN.pdf
- MS Essentials 17: Pain and Sensory Symptoms Multiple Sclerosis Society (UK) http://www.mssociety.org.uk/support_and_services/free_publications/ms_essentials_17.html
- Manage Your Pain: Practical and positive ways to adapt to chronic pain By Michael Nicholas, Allan Molloy, Lois Tonkin and Lee Beeston ABC Books, Sydney, Australia (2007)

Glossary of terms

Abdomen: The part of the body between the rib cage and the hips/pelvis. Commonly referred to as the tummy or belly.

Analgesic: A remedy or drug that relieves or removes pain.

Anti-convulsant: A drug used to treat convulsions (seizures).

Anti-depressant: Any sort of drug used to treat depression.

Anti-spasmodic: A drug used to treat spasms.

Cannabinoids: Active components of the drugs found in marijuana.

Carer: Someone who cares for, looks after or helps others.

Clinical psychologist: Psychologist who has at least six years of university training and is specialised in the assessment, diagnosis and treatment of psychological and mental health conditions.

Deconditioning: The loss of strength and fitness caused by decreased exercise and activity.

Exercise physiologist: Four-year university-qualified allied health professional who has expertise in the delivery of exercise, lifestyle and behavioural modification programs for the prevention and management of chronic diseases and injuries.

Hydrotherapy: The use of water in the treatment of disease. In MS, hydrotherapy usually refers to water-based exercises.

Medication: The use or application of medicine or drugs to treat a disease or problem.

Multiple sclerosis (MS): MS is a chronic disease of the central nervous system (CNS: brain, spinal chord and optic nerves). In MS, the immune system mistakenly starts to attack myelin, the protective coating around the nerve cells in the CNS that assists nerve conduction. The nerve cells themselves can also be damaged. These attacks on myelin produce 'scarring' or 'plaques' in the CNS. These scars slow or interrupt the transmission of nerve impulses, resulting in the symptoms of MS. The progress, severity, and specific symptoms of MS are unpredictable and vary from one person to another.

Musculoskeletal: A general term which is defined as relating to muscles and the skeleton. The musculoskeletal system involves the muscles, bones, joints (the place of union between two or more bones), ligaments (a fibrous band of tissue connecting bones), tendons (a fibrous band of tissue connecting muscle with bone), and the biology of the musculoskeletal system.

Neurological: Dealing with the nerves and nervous system, including the brain and spinal cord.

Neurologist: Specialist medical doctors who treat neurological problems. This includes diseases of muscles through to disorders of cognitive function and behaviour.

Neuropathic pain: Pain caused by damage to nerves or by damage to the brain, brainstem, or spinal cord. Also called 'pain due to neurological causes', neurogenic pain or central pain.

Nociceptive pain: Pain caused by damage to tissues and bones in the body. Also called 'pain due to musculoskeletal causes'.

Opiod: A medicine that contains opium or a medication that has the same effects as opium.

Pain: An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or experience described in terms of such damage.

Physiotherapist: Four-year, university-trained clinician who has expertise in rehabilitation and the management of physical symptoms and movement problems. They use methods such as exercise, motivation, adapted equipment, education and advocacy.

Psychiatrist: A medical doctor who specialises in the diagnosis, treatment and prevention of mental, emotional and behavioural disorders. Psychiatrists can prescribe medication and some provide psychological therapy.

Rehabilitation specialist: A medical doctor who provides expertise in the prevention, assessment, management and medical supervision of a person with a disability, until that person has attained an optimal level of performance or quality of life.

Wincing: To shrink, draw back or flinch, as if in pain.

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