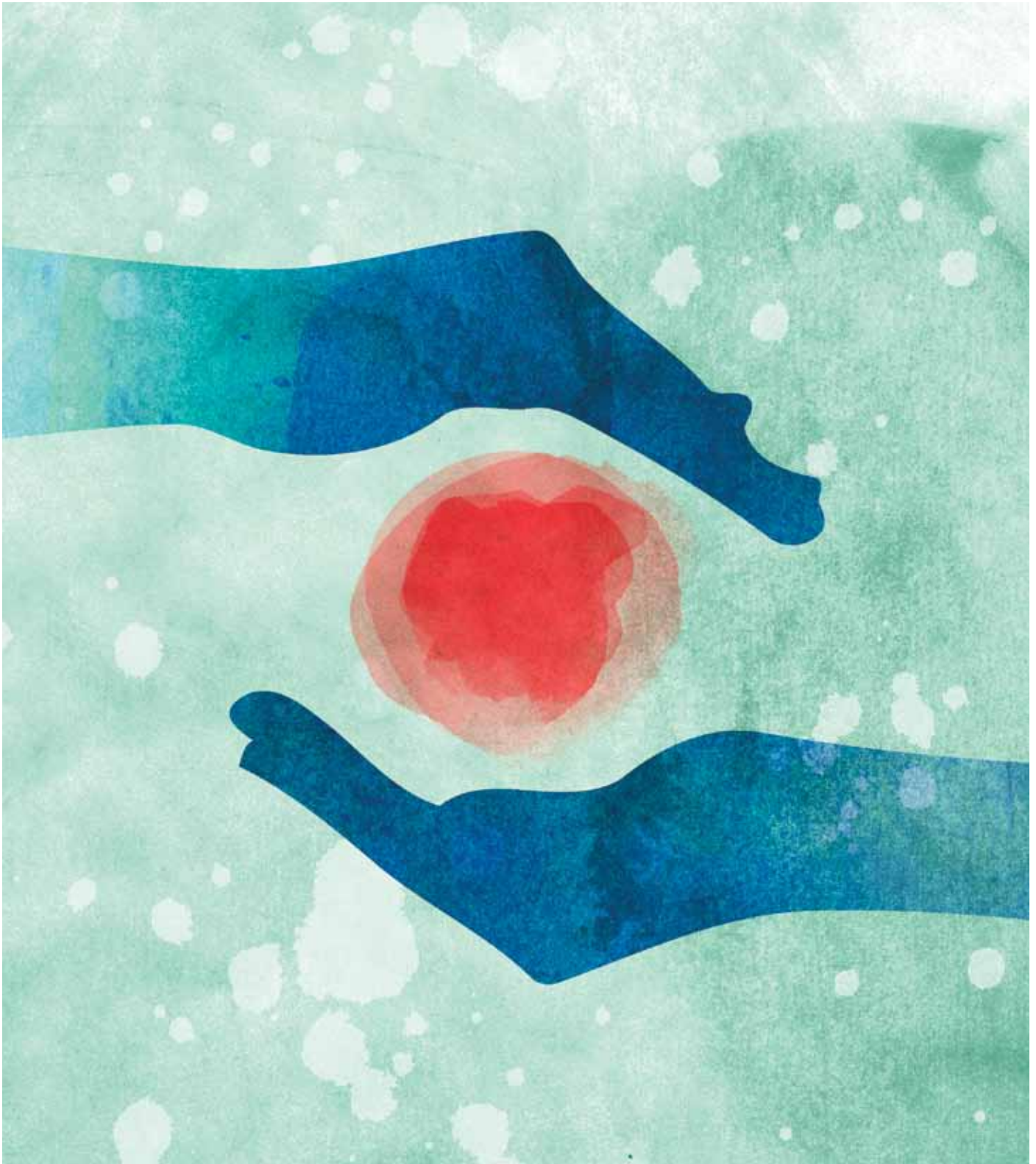


Managing a Relapse

For People Living with MS



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Giving Life Back



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MS Australia strives for a world without multiple sclerosis (MS) through quality research and for service excellence to people with MS, their family members and carers.

MS information and support line:
1800 042 138

Acknowledgements:

Elizabeth Atkin, Community Support Worker,
MS Australia – ACT/NSW/VIC

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MS Australia – ACT/NSW/VIC

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MS Australia – ACT/NSW/VIC

MS Australia – ACT/NSW/VIC Publication Review Committee:

Dr Gary Fulcher, Senior Clinical Psychologist

Angela Geltch, Information Line Officer

Dr Elizabeth McDonald, Medical Director

Helena Paul, MS Nurse

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MS Australia - ACT/NSW/VIC

The Nerve Centre
54 Railway Rd,
Blackburn, Victoria 3130

p: (03) 9845 2700

w: www.msaustralia.org.au/actnswvic

Disclaimer: Information contained in this booklet should not be used for individual medical advice. Readers must seek their own medical advice as required.

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Introduction

Australian research shows that about 85 per cent of people diagnosed with multiple sclerosis (MS) initially experience relapsing-remitting MS. This type of MS is characterised by unpredictable relapses, also referred to as exacerbations, bouts, episodes, attacks or flare-ups.

The unpredictable nature of relapses can make them challenging to predict, diagnose and manage. They can vary in length and severity, causing a range of symptoms that may be difficult to detect against a backdrop of other MS-related and non-MS-related health issues.

Some people with MS experience relatively few relapses, while others may experience them more frequently. Every person's experience will be different, so it is essential to gain as much knowledge as possible about MS and how it affects you as an individual.

While avoiding a relapse may be the priority, being prepared for one can assist in your overall management of the disease and give you a sense of control over, what can often be, a stressful situation.

This booklet aims to help you manage your relapses by:

- providing information on how you may be able to identify a relapse and informing you of some of the factors that can impact on relapses.
- suggesting things you need to think about to plan for a relapse, including a template to help guide you through this.
- providing information on some of the things you may experience during this time.

If you have been diagnosed with relapsing-remitting MS it is likely that you have already experienced a relapse. However, sometimes it can be difficult to determine exactly what type of MS you have. It is best to speak to your neurologist who may be able to help you to determine the course of MS that you are dealing with.

For more general information about MS, please call our information and support line on 1800 042 138 (Freecall™) and we will provide you with the resources that are most relevant to your information needs.

What is a relapse?

The central nervous system (CNS) is made up of the brain and the spinal cord. In MS, the immune system attacks myelin – a protective sheath which surrounds the nerve fibres of the CNS.

When the immune system continues to attack nerve fibres, causing damage to myelin, this is referred to as inflammation.

When new inflammation and/or damage to myelin occur in the brain and spinal cord, a relapse occurs. Damage in different parts of the CNS will interrupt different messages and lead to different symptoms. Common symptoms associated with a relapse include issues with fatigue, balance, eyesight, bladder, abnormal sensations, memory and thinking, and mobility.

A relapse may also be referred to by other names such as an exacerbation, bout, attack, flare-up or episode.

Although the definition of a relapse may seem quite complicated, it is important that you begin to develop an understanding of what a relapse is so that you can discuss it with your healthcare team.

A relapse is formally defined as the development of new symptoms, or the temporary worsening or recurrence of old symptoms, which is not caused by an infection or any other cause and lasts more than 24 hours.

How do I know if I am having a relapse?

A relapse needs to occur at least 30 days after any previous episode to be considered a new relapse. A relapse may occur quickly with a sudden and intense onset of symptoms, or gradually with symptoms appearing over a few days or weeks. While some people may experience mild symptoms, for others they may be more noticeable.

It can be difficult to know if you are having a relapse. Most people with MS will have a range of fluctuating symptoms at any given time, so

it can be hard to tell if an increase in symptoms is part of the variability of the MS or if it is in fact a relapse. Changes in symptoms should be referred to your neurologist. Your neurologist needs to be aware of symptom changes to determine how often you are having a relapse and if your current treatment is working for you.

Doctors and neurologists can even find it difficult to diagnose a relapse and sometimes they are diagnosed in hindsight. This is because anything which causes an increase in a person's core body temperature can mimic MS symptoms.

What can mimic a relapse? (pseudoexacerbations)

When a person with MS has a rise in their core body temperature and experiences MS symptoms, it is referred to as a pseudoexacerbation. A pseudoexacerbation is a temporary worsening of symptoms that does not indicate actual inflammation or damage to myelin but which is brought on by other issues. A range of things can cause a pseudoexacerbation. They include other illness or infection, exercise and an environment that is too warm.

Strenuous exercise can cause relapse-like symptoms because it results in a temporary increase in your core temperature. Research conducted shows that relapse-like symptoms usually settle within half an hour of stopping exercise and cooling down, and that exercise does not cause any permanent damage for people with MS.

Resting and taking a cold drink or shower should help to bring down the body's core temperature and reduce the heat-related symptoms caused by a pseudoexacerbation.

“

Getting to know what can trigger certain symptoms can help; you feel less panicked

” – Jeff



If the increase in symptoms is due to an infection, it is essential that you see your doctor and treat the underlying cause of the infection to reduce the symptoms. Once the infection is identified and treated, the relapse-like symptoms will usually settle within a day. Nevertheless, it is important to note that infection can sometimes trigger a relapse so look out for possible urinary tract, cold or flu infections.

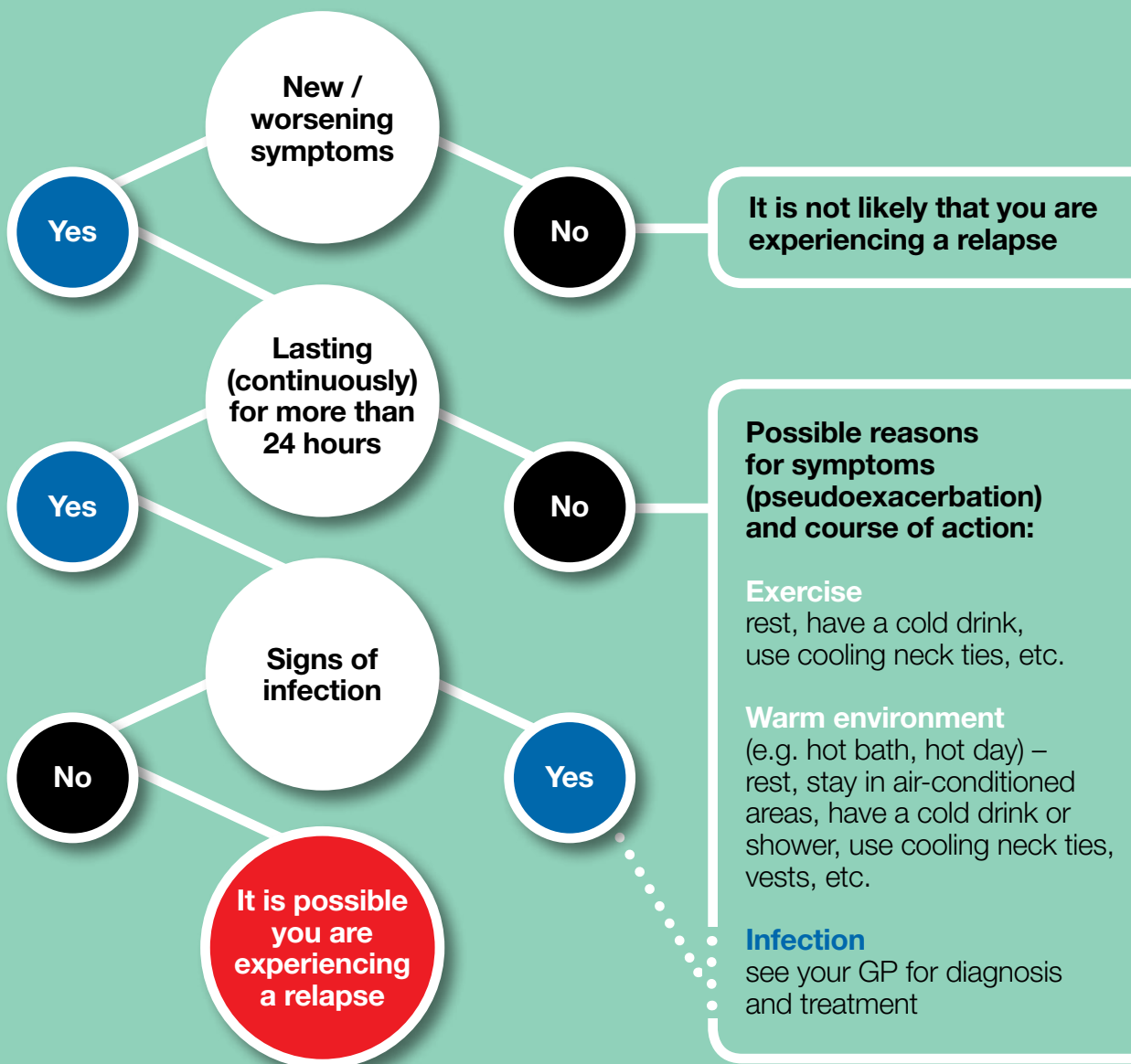
How long does a relapse last?

Relapses differ widely from person to person, and the symptoms, severity, frequency and

length of a relapse will often vary over time within the same person.

Although the experience of having a relapse can be overwhelming, relapses may often be mild and the symptoms can resolve within a few days or weeks. Occasionally it may take a few months, and while some people may regain full function following a relapse others may experience some ongoing reduced function.

In summary: What is a relapse?



Factors that impact on a relapse

A number of factors may impact on a relapse. Some factors may influence the severity and frequency of relapses, while others may improve your capacity to cope with relapses when they occur.

Medical treatment

When it comes to relapses, managing the underlying disease activity is important. Medical treatments for the MS itself can reduce the frequency and severity of relapses (see the chapter on 'Treatment options' on page 7).

Living well

Taking a proactive approach to your overall health management can help optimise your capacity to cope with a relapse if one does occur. Improving your overall health may also contribute to reducing the severity and frequency of relapses.

Some of the things that you can do that may help you to cope better include:

- Getting adequate sleep
- Maintaining good nutrition and sufficient hydration levels
- Refraining from cigarette smoking and other harmful substance use
- Maintaining hygiene and protecting yourself against other infections
- Addressing other (non-MS-related) health issues
- Managing your MS symptoms effectively (not just the MS itself)
- Maintaining a good level of fitness or ensuring that you remain active
- Getting sufficient and safe sun exposure
- Adopting stress-management strategies, managing any mood issues (such as anxiety and depression) and avoiding negative thinking
- Adopting fatigue-management strategies and trying to stay in a comfortable temperature wherever possible
- Socialising with friends, family and the community, or with others who are experiencing the same issues and concerns.

Manage your fatigue

The 'Be prepared' chapter on page 9 of this booklet provides information on some of the health professionals who can help you to devise fatigue-management strategies.

Physical activity

Getting regular exercise is part of maintaining overall good health. Physical activity can help to maintain strength and flexibility and is considered to be good for stress management. It has also been shown that exercise promotes a healthier CNS and may even assist with minimising fatigue.

It is important for people with MS to implement a program that is suited to their needs and capabilities. Although there are benefits to exercising, you need to ensure that you are not overdoing it. To maintain a safe balance, it is recommended you consult with a physiotherapist before starting an exercise program.

It is important to keep your core body temperature down during exercise and to rest afterwards.

Stress and mood management

Psychological factors affect the overall quality of health and life for a person with MS, so talking to someone about how you are feeling or making contact with a GP for assessment and monitoring is worthwhile.

These factors interact with how you see yourself, how you relate to your family and work colleagues, as well as how you approach the management of your health.

When you are living with MS, there are times when it becomes necessary to make changes to how you do things so that you can manage your symptoms. Stress and mood issues can be demotivating at these times. Learning how you can possibly manage your mood and stress can help you to feel as though you have more control over your situation.

Avoid infections

Upper respiratory tract infections (i.e. colds and flus) aggravate the immune system and can trigger relapses. Due to this, it is recommended that you speak with your doctor about



immunisation against seasonal viruses to ensure that you are protected. Urinary tract infections can also be problematic for the same reason so adopting and maintaining good hygiene practices is vital.

Complementary therapies

Many people with MS pursue complementary therapies such as massage, yoga or tai chi to optimise their overall health. Make sure you let your doctor or neurologist know if complementary therapies are part of your healthcare to ensure they do not adversely affect you or interfere with your medical treatment.



I'm continuing to learn how to listen to my body; to know when I need to take time to rest or to get more exercise – and to remember that relapses happen but not to freak out if I have a sore hand for a day



– Dani

Pregnancy and relapse

Women with MS usually experience a relapse-free period during pregnancy, particularly during the second and third trimesters. This is a result of hormonal changes during pregnancy. Although there is an increased risk of a relapse in the first three months after child birth, the chances of a relapse return to pre-pregnancy levels after this period.

Exclusive breastfeeding during the first few months after giving birth may reduce the chance of a relapse; however, this is not a guarantee and the physical stress of breastfeeding and inadequate sleep are factors that will need to be taken into consideration. Contact our information and support line on 1800 042 138 for further reading and information about pregnancy and MS, and speak to your doctor or neurologist.

In summary: Factors that impact on a relapse

MEDICAL TREATMENT

PREGNANCY & BREASTFEEDING

MANAGING FATIGUE

AVOIDING INFECTION

PHYSICAL ACTIVITY

COMPLEMENTARY THERAPIES

STRESS & MOOD MANAGEMENT

Treatment options

Your doctor or neurologist is the best person to communicate with about the medications you should be taking during a relapse. It is important for you to know that there is a difference between the immunotherapy medications used to help treat MS and the medications that may be used to treat your symptoms should you have an intense relapse.

The medicines used to treat a relapse, or **symptom-management drugs**, include corticosteroids (steroids). They are used to manage intense relapses by easing inflammation in the affected area.

The medicines used to treat MS are **disease-modifying drugs**, also known as immunotherapies. They are the recommended available treatments for MS and work to reduce disease activity in the central nervous system.

How do steroids work?

The medicines used to treat a relapse, or symptom-management drugs, include corticosteroids (steroids).

Steroids are drugs that mimic the effect of hormones that are naturally produced in the body. When steroids are given so that they exceed the body's natural levels they can suppress inflammation, reducing the signs and symptoms of inflammatory conditions such as MS.

Unlike disease-modifying drugs, these drugs only treat the symptoms of a relapse, not the actual MS. They can help settle the symptoms you are experiencing and, in some cases, reduce the length of a relapse and lead to a quicker recovery.

What steroids are available for treating relapses?

The most common steroids used for MS-related relapses are prednisone (Panafcort, Sone) which is given in an oral form, and methylprednisolone (Solu Medrol, Depo-Medrol) which is administered intravenously.

“

Keep taking your medication and don't stop even if you think it's not helping. I learnt the hard way that it really does help. Also, keep smiling... it makes everyone wonder what you've been up to

”

– Amanda

How will I know if I need steroid treatment?

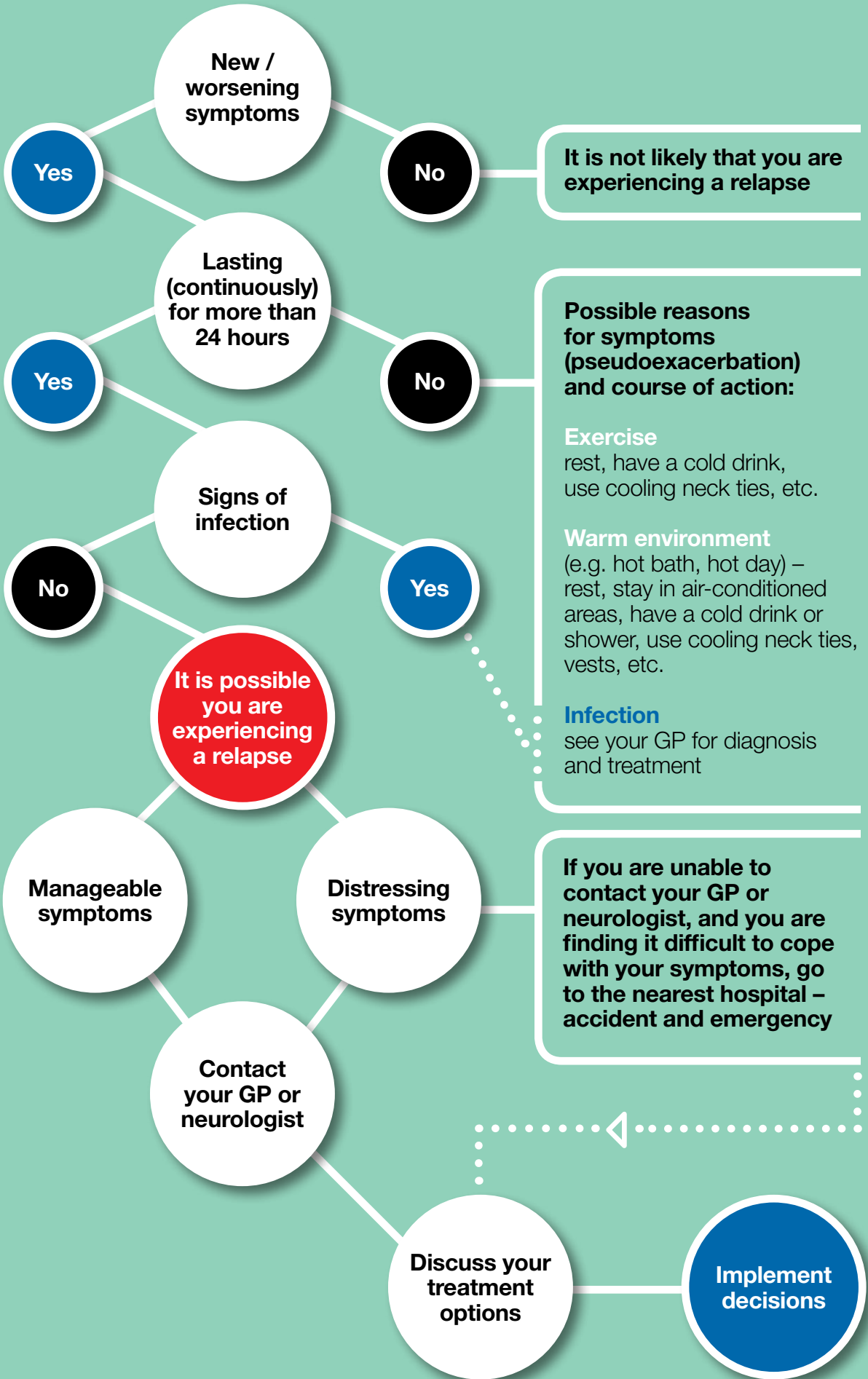
It is important to note that relapses will be assessed on an individual basis. Your doctor or neurologist will consider a number of things including your symptoms, the severity of the relapse and the functional loss you are experiencing, as well as the side effects of the steroid treatment. It is essential to report your relapses to your neurologist to ensure you are receiving the best possible treatment for your MS.

Medical treatments for MS

Disease-modifying drugs, also known as immunotherapies, are the recommended available treatments for MS. One of the ways in which immunotherapies work is to reduce the frequency and severity of relapses. It is important to take these treatments as directed by your neurologist or MS nurse. For information on the available treatments for MS contact 1800 042 138 (Freecall™).

It is important that you continue taking your immunotherapy drugs during a relapse. It may be helpful for someone to assist you to ensure that you continue your treatment during a relapse, particularly if you aren't thinking clearly or if you're experiencing other symptoms.

In summary: Treatment options



Be prepared

While it may not be possible to predict when a relapse may occur or how long it will last, planning ahead so that you are as prepared as possible can help to increase your sense of control over the situation.

A relapse-management plan

There are areas in your life that will be impacted by a relapse so having a relapse-management plan in place can be helpful. While most people with MS may not want to think about a relapse when they are well, it helps to accept that this is an aspect of the condition. The more prepared you are, the better you can manage the impact on your health and your life.

It is also important to take into account that during a relapse you may have difficulty focusing, or become temporarily forgetful or exhausted at a time when it is particularly important to make suitable arrangements so that you are better able to cope. That is why planning ahead can be very useful.

Below you will find some of the things that you can think about when preparing a relapse-management plan and the 'Relapse-management plan template' on page 12 is a good place to start.

Emotional preparation

When a relapse occurs, you may experience a range of feelings. You may feel that you should have been able to avoid the relapse; you may feel angry that this has happened at this particular time or that it has happened at all; you may feel fear about what the future holds for you; or concerned about the impact that MS will have on your relationships, your work and your capacity to live life to the fullest.

It may also be the case that each relapse will trigger different emotions, depending on the symptoms you are experiencing. For example, if you most commonly experience sensory issues during a relapse, having a relapse that affects your eyesight may have a greater impact on your emotions.

Try not to lose hope. Relapses can take you by surprise and the symptoms may be difficult to deal with, but you don't have to lose your

independence or stop doing the things that you love most. The aim is to live your life as best you can despite the symptoms of MS. It is important to know that your initial reactions will likely resolve over time. However, if these feelings are having a considerable impact on your life it may be beneficial to see a clinical psychologist or counsellor. These professionals can help you to understand how to manage your feelings. It is also not uncommon for a relapse to lead to depression, so be alert to the signs that you may be depressed and speak to a trusted friend or your doctor about it.

A relapse can impact on the lives of those around you. Your loved ones may experience grief, anxiety, anger and guilt. Being aware that they may have these feelings during a relapse, and that it is a normal reaction, can help all of you to manage through this difficult period. It is important for family members who are having trouble coping to seek information and support. Our information and support line can be contacted on 1800 042 138 and welcomes calls from family members and carers of people with MS.

Practical preparation

There are two things that you can attempt to do before a relapse that may assist you to manage better when it does occur:

- Make some plans around how you will medically manage your MS, including relapses, and keep your MS information well organised and accessible.
- Try and identify some of the areas of difficulty you may experience when you are dealing with a relapse.

Note changes in your symptoms

Keep a note of changes in your symptoms and how they are affecting you (severity, length of time, if anything eases symptoms, what has helped in the past, etc). It can also help to note any physical or emotional events prior to any changes.



Talk to your healthcare team

One of the first conversations to have with your neurologist should be about what they suggest you do in the event of a relapse and how you can be more prepared.

Speak to your neurologist about:

whether you should phone them or an MS nurse who works in their clinic during a relapse (or perhaps email a list of symptoms and their severity and duration).

how long you should wait for your symptoms to settle.

what they suggest you do if they are on leave.

which hospital you will be admitted to should you need hospital care.

when it would be appropriate for you to go immediately to accident and emergency.

providing you with a letter to confirm your diagnosis. Relapses can occur during holiday periods or when you're away from home so a letter will be useful should you need to present to accident and emergency.

It is also important to have a discussion with your GP about how you can work together in terms of your MS. If you think you are having a relapse your GP may be your first port of call. They will be able to tell you if there is an underlying infection or rule out any other health conditions. Your GP may need to discuss options with you for further managing your relapse and make appropriate referrals to other health professionals.

Ensure easy access to your information

Keeping all your medical information together – information relevant to the medical management of your MS and the contact details of your healthcare team – to be easily accessed by yourself or by others on your behalf, can be extremely helpful.

It is advisable that you also keep information on medications and symptom management, as well as any information on any patterns that you experience at the onset of a relapse, for future planning.

During a relapse, looking for important contacts and information can be stressful and a waste of energy. The 'Relapse management plan template' on page 12 is a suggested way of recording your MS-related information and it can be adapted to suit your individual needs. It may also be a useful tool for those in your support network should they need to take the lead in a relapse situation.

Inform your support network

Ensuring that your family understand the nature of your MS and the nature of relapses is important. They will need to know that relapses are a possibility, that you will be affected when you are experiencing one and that you may need active treatment at that time. It is important to discuss the details of your relapse-management plan with your support network so that they are just as prepared as you in the event of a relapse.

Consider your roles and responsibilities

In planning for a relapse you will need to think about your roles and responsibilities in life. Consider what things you need to make

arrangements for in the event that you are temporarily too unwell to do them.

For example if you care for babies, children, pets, ageing parents or a person with a disability you will need to think about who can assist or fill in for you when you are unwell.

Some of the things you can ask yourself include: Who can do my household duties if I am temporarily unable to do them? Which of those duties can be put off and for how long? In the event that I need assistance with doing things for myself, who can I call on?

During a relapse you may require babysitting, garden maintenance and/or domestic assistance, such as cleaning, grocery delivery, meal preparation and other services that are relevant to your life circumstances. Making a list, prior to a relapse, of the people or services that can provide help in these areas can ensure that the people around you can better assist you during a relapse.

You may also need to think about your circumstances at work. Make it your business to know what your leave entitlements are, how much leave you have accrued, and how much time you can have off before it is necessary to provide a medical certificate.

Other things to consider, if you are temporarily unable to work, are things such as: What timeframes do I give my employer? If I can go to work but I'm not in top form how will I explain this? If my relapse is mild, do I even need to tell my employer at all?

Disclosing your MS

Because of the nature of relapses, you will need to consider who you are going to disclose your diagnosis of MS to. You may want to consider how you are going to impart this information.

When telling your children, for example, you need to think about their age and their capacity to understand the condition. These types of discussions are probably more manageable when you are calm and well.

Telling your employer or manager will need a very different approach. Some people choose to disclose symptoms rather than the condition itself.

Deciding who to tell about your MS is an important decision to consider and something that you will need to think through carefully. For resources about disclosing your MS, contact our information and support line on 1800 042 138 (Freecall™).



My tips: lower your expectations of what you can achieve in a day, accept any help offered and go to bed early



– Dianne

Away from home

It is a good idea to plan for the possibility of a relapse prior to travelling away from home. If you're travelling overseas carry Australian Consulate phone numbers for relevant countries with you. Take your MS identification card with you (this ID card can be used to prove you have MS and can be obtained from MS Australia – ACT/NSW/VIC by contacting 1800 042 138), as well as a letter from your GP or neurologist confirming your diagnosis.

This letter should include a list of prescribed treatments and an original prescription for each medication you are carrying. If you need to discuss the issue of travelling with injectable medications, speak with a registered MS nurse by calling our information and support line. It is also worthwhile doing some research on the medical systems in the countries you are planning to visit and ensuring you have adequate travel insurance.

Relapse-management plan template

My immediate contacts

These are the people who need to know you are having a relapse. They are people who will help, or who will take care of you, children or pets. They may include your spouse, family, friends, neighbours, work and place of study.

Name: _____	Name: _____
Phone: (Home) _____	Phone: (Home) _____
(Mobile) _____	(Mobile) _____
Name: _____	Name: _____
Phone: (Home) _____	Phone: (Home) _____
(Mobile) _____	(Mobile) _____
Name: _____	Name: _____
Phone: (Home) _____	Phone: (Home) _____
(Mobile) _____	(Mobile) _____

My medical contacts

This section may include your GP, neurologist, all-night doctor, 24-hour pharmacy, the accident and emergency of your local hospital, and ambulance service.

GP	24-hour pharmacy
Address: _____	Address: _____
Phone: _____	Phone: _____
Neurologist	Accident and emergency
Address: _____	Address: _____
Phone: _____	Phone: _____
All-night doctor	Ambulance
Address: _____	Address: _____
Phone: _____	Phone: _____

Some phones or phone applications may allow you to create a contacts list in which you can include the details of the people you need to call during a relapse. Alternatively, you may like to tape a contact list by the phone at home for easy reference or keep a small phone book. Try to make these numbers as accessible as possible.

My links

These links might include information providers on MS issues and symptom management, your community support worker (CSW)/social worker/MS nurse (see page 16 for information about these healthcare professionals), local peer support groups, and other services such as physiotherapy. If you are unsure of who to include in this list, your CSW/social worker/MS nurse can help you tailor these links to meet your individual and changing needs.

Information and support line: 1800 042 138 (Freecall™)

CSW/social worker/MS nurse

Phone: _____

Local support group

Meeting time: _____

Meeting place: _____

Phone: _____

Occupational therapist

Phone: _____

Physiotherapist

Phone: _____

Other:

Phone: _____

Other:

Phone: _____

You may have some other things such as an exercise plan, fatigue-management recommendations or speech-pathology exercises that you would like to store together with the contact details of the health professionals that you are working with to manage your symptoms.

My medical information

Medicare number: _____

DVA number: _____

Pension number: _____

I was diagnosed with multiple sclerosis (MS): / / (or approximate months/years)

Medical/hospital insurance fund membership number: _____

The symptoms I commonly experience with my MS are:

Medications (including herbal/complementary therapies) I am currently taking:

Medication:	Dosage:
_____	_____
Medication:	Dosage:
_____	_____
Medication:	Dosage:
_____	_____
Medication:	Dosage:
_____	_____
Medication:	Dosage:
_____	_____
Medication:	Dosage:
_____	_____

Known allergies include:

Additional information:

Whether you note all these details in this template, in an exercise book or keep them in a folder, the idea is to ensure that you can find all the information you need at once. It makes it especially easy if you need to visit a hospital or you need someone to quickly locate your medical information for you. It would also be useful to keep any other documentation such as a letter of diagnosis or referrals and prescriptions with this medical information. Make copies of these documents, as you will be asked to present them in various circumstances, and keep the originals in a safe place.

Assistance in my home

These include the services or agencies that you may choose to use during a relapse. You may wish to discuss your specific needs with a CSW/social worker. Some examples include child care, financial assistance, supermarket home delivery, local cleaning service, and local gardening or lawn mowing service.

Organisation: _____	Organisation: _____
Phone: _____	Phone: _____
Organisation: _____	Organisation: _____
Phone: _____	Phone: _____
Organisation: _____	Organisation: _____
Phone: _____	Phone: _____

Knowing about the local and other services you can access before a relapse occurs can save you much time and energy. The 'consider your roles and responsibilities' section on page 10 in this booklet suggests some of the things you may need to think about when identifying these services.

Relapse-management template review dates

Last reviewed: _____	Last reviewed: _____
Last reviewed: _____	Last reviewed: _____
Last reviewed: _____	Last reviewed: _____
Last reviewed: _____	Last reviewed: _____
Last reviewed: _____	Last reviewed: _____

Keeping your plan as up to date as possible will ensure that you are prepared when a relapse occurs. You may like to make copies of this template so that you can update it as many times as you like. After a relapse is a good time to review your relapse-management plan.

For information on MS, as well as MS services and programs, please contact our information and support line: 1800 042 138 or msconnect@msaustralia.org.au

Coping during a relapse

If you know that you are experiencing a relapse, it is important to keep in mind that it will settle down of its own accord. The main thing is that you manage the practical, psychological and physical impact of the relapse and try and reduce any further risk to your health and wellbeing during this time.

If you have a relapse-management plan in place, now is the time to use it. Work through the plan, closely with your family and friends so that it works well for all of you.

If you don't have a plan in place, now may not be the best time to create one. Wait until your relapse symptoms have settled. However, it is important to enlist the help of your family and friends. Let them know what would be helpful to you during this difficult time.

If you are not sure what steps to take, ring our information and support line on 1800 042 138 for some initial advice.

When should I see my GP?

As soon as you can, make an appointment to see your GP. If you are experiencing a relapse and your symptoms are fairly mild, your doctor might wait and see if the symptoms clear on their own. If your symptoms are more severe or continue to get worse, your doctor may prescribe treatment (see the chapter on 'Treatment options' on page 7 for more information) to assist with your recovery and refer you to your neurologist or other health professionals who can help.

My neurologist is always busy, how do I get him to see me?

To ensure your neurologist sees or contacts you promptly, it is important to inform the receptionist that you are experiencing a relapse. It may be helpful to describe your symptoms and highlight how they are affecting you on a day-to-day basis.

If your neurologist or GP is not available and your symptoms are getting worse, go to accident and emergency. To avoid having to wait a long time to receive medical attention or treatment, take relevant information with you such as a letter of diagnosis, medication, referral, etc. It may also

help to take a support person with you as well as a list of some of your symptoms. If you have been to see your GP they may ring ahead to alert the hospital.

What to say when seeking a timely appointment with your busy neurologist:

“

I am experiencing new symptoms and a worsening of my old symptoms. My [insert symptom e.g. vision is blurred] and I'm [insert symptom e.g. losing my balance]. I feel [insert feeling e.g. worried] about what is happening to me. Is it possible for me to see or talk to the neurologist to find out what I need to do and how quickly I can see him/her?

”

I am feeling overwhelmed. Which healthcare professionals can help me?

During a relapse, it is important to manage any symptoms that are having an impact on your life. There are a range of health professionals, within our organisation and within the community, who can assist you with managing the issues brought on by relapses. It is beneficial to have an understanding of the health professionals that are available to help and how they can assist you.

An **MS nurse, community support worker (CSW) or social worker** can work with you to develop a personalised relapse-management plan and to devise strategies that address your MS-related concerns. A CSW/social worker/MS nurse can also assist you to access various health and community services.

An **occupational therapist (OT)** can assist you to address temporary functional difficulties that you are experiencing either at home or at work. They can especially help when these are tasks that you are normally able to do, or that

you need to be able to complete so that you can manage your life and responsibilities.

A **physiotherapist** can devise tailored programs to help you increase your physical strength and fitness and optimise mobility, balance and coordination. In the event of a relapse, physiotherapists can advise you on the appropriate level of exercise and devise a fitness regime to follow as you recover.

A **psychologist, social worker** or **counsellor** can assist you to manage stress, anxiety and depression and can help you consider the impact of MS on your relationships.

Neuropsychologists are concerned with understanding how the brain works in the areas of thinking, memory, behaviour and personality. There is also a focus on how changes in the brain affect these areas. Neuropsychologists can help you identify which brain functions, if any, have changed and they can also advise on ways to manage such changes.

In the event of a relapse, you may need to consult a number of different health professionals to address your concerns and to assist in your recovery. You may not need to make contact with all of them and this list is by no means exhaustive. No matter which health professionals you choose to have as part of your healthcare team, they can work with you, and together, to ensure that all aspects of your individual situation – including your physical and emotional wellbeing – are addressed.

I am feeling very emotional, is this normal? What should I do?

During a relapse, it is normal to experience an element of grief for the loss of health, functionality and lifestyle. You may have depressing or fearful thoughts. Remember, that it is normal to feel this way and that it won't last forever.

Some medications may also be impacting on your emotions. If you are finding it hard to sleep well during the night, you may find it more difficult to deal with everyday situations which would not usually be a problem.

Make an appointment to see your GP for a review and discussion about medications and the impact

they are having on your life, and try to arrange some counselling sessions – they can also be very helpful during this time.

How may a relapse affect my thinking?

Because a relapse is often stressful, many people can feel distracted and a bit overwhelmed and may have problems thinking through complex tasks. These mild thinking problems are fairly common during a relapse and will become less of a problem as you begin to manage your relapse.

In some cases during a relapse, you will have more obvious problems with thinking. You may feel groggy, very tired, your speed of thinking may be affected and you may have trouble focusing your attention. If these symptoms come on quite suddenly, it's possible you're experiencing a cognitive relapse.

If this occurs, try not to be too alarmed as these symptoms will mostly settle in about six to eight weeks. However, if they interfere with your ability to do the important tasks in your life, an OT and a neuropsychologist (definitions covered earlier in this chapter) can work with you to develop strategies to help you manage.

Often a neuropsychologist in your local area will have knowledge about other services in your area that you may need to access. For example, practical issues might be attended to by other healthcare professionals, such as an OT, CSW or social worker.

Overall, during a relapse is not the best time to be making important decisions such as changing jobs or leaving work, ending or beginning relationships or moving house. It's best to leave big decisions until you are feeling better. Instead, focus on managing your symptoms and getting on with the important tasks in your life during this period.



Occasionally I do have to take time out. Like right now. I haven't done too much, but my organisational skills seem to be hiding somewhere

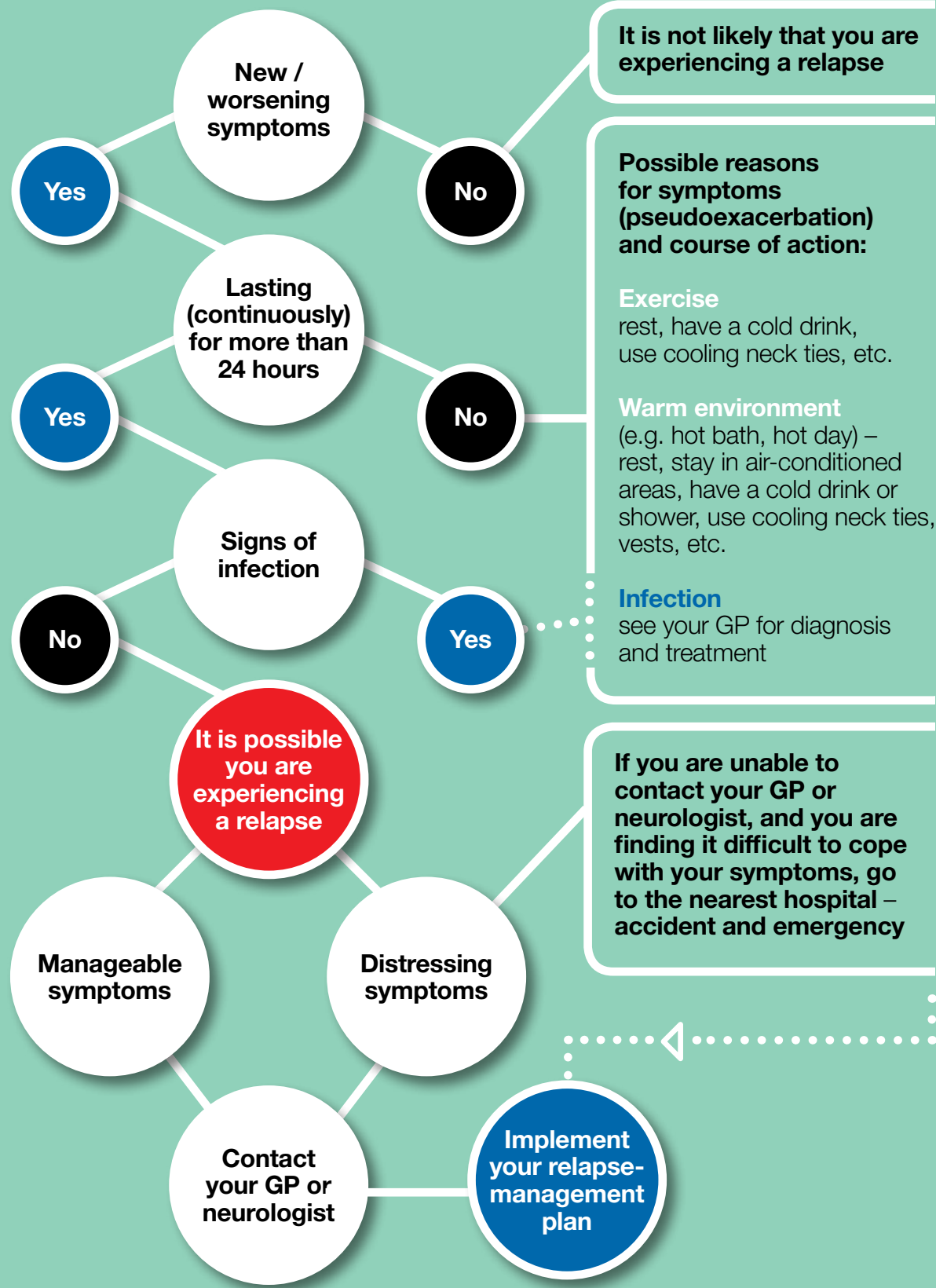


– Cat

Should I be driving my vehicle at this time?

If you need to drive, consider whether you are well enough to do so safely. If not, make other arrangements, not only for the short-term (to get home or to the doctor's surgery) but for as long as you are experiencing symptoms. Talk to your doctor about when you may be able to resume driving.

In summary: Coping during a relapse



After a relapse

Some people do recover fully from a relapse without any long-term symptoms. However, the period of time after a relapse can be challenging – every person and every relapse is different.

Following up on a few things after the relapse has passed may help to get you on your feet quicker or help to ensure that you are feeling more prepared the next time you have a relapse.

See your neurologist

It is important that you make an appointment to see your neurologist after your relapse to discuss your treatment and how it is working for you, as well as the outcomes of the relapse.

Emotional impact

It is important to give yourself time to recover from the impact of a relapse. Do not be too hard on yourself if you don't yet feel completely well. You may be emotionally drained after a relapse or experience a bout of depression. Speak to a professional about how you can address these issues. Your GP is a good starting point.

Rehabilitation

Depending on the symptoms you are experiencing, rehabilitation following a relapse is likely to include a team of health professionals (see page 16 to find out more about who can help).

For example, if you are experiencing physical issues after a relapse it may be a good idea to see a physiotherapist as it has been shown that people can benefit from engaging in active exercise.

Physical activity can also help to maintain strength and flexibility and is considered to be good for stress management.

After a relapse, you may also experience some psychological or cognitive (memory and thinking) issues. If these symptoms haven't resolved after two months, make an appointment to see your doctor or neurologist. Contact our information and support line on 1800 042 138 if you would like to be directed to more information on symptom-management strategies.

Review your relapse-management plan

After a relapse is a good time to review your relapse-management plan. Are there things that didn't quite work the way you wanted them to? Was there anything that you forgot to include that might be useful next time? Are there any services or contact details you need to update?

Keeping your plan as up to date as possible ensures that you are prepared when a relapse occurs.

Further reading and resources

Accessing health professionals and services

MS Australia – ACT/NSW/VIC offers a variety of programs to help people with MS effectively manage and cope with multiple sclerosis (MS). Whether you are a person with MS, or a family member or carer of a person with MS, we can assist you to meet your needs.

Living with MS can be challenging at times, but through the support offered by our organisation, no-one has to face these challenges on their own. We provide information on MS and MS-related issues, as well as assessment and referral services to connect people with MS and their caregivers to vital community support resources.

We are also committed to ensuring our service is sensitive to the gender, religion and cultural or linguistic background of our clients. To speak to our staff using a telephone interpreter service, contact the Translating and Interpreter Service (TIS) on 131 450. Ask for an interpreter who speaks your language and provide the number of our information and support line (1800 042 138 – local charges apply and higher charges apply to mobile and public telephones).

Contact us:

1800 042 138 (Freecall™)
www.msaustralia.org.au

Other helpful resources

Multiple sclerosis: The questions you have, the answers you need. Kalb, R. 5th edition. Demos: New York, 2001.

Multiple sclerosis for dummies. Kalb, R. Holland, N. and Giesser, B. Wiley Publishing Inc: Hoboken, NJ, USA, 2007.

MS Essential 01: Managing a relapse

Multiple Sclerosis Society (UK)
www.mssociety.org.uk

Exacerbations

National MS Society (USA)
www.nationalmssociety.org

MS Learn Online: Understanding exacerbations

National MS Society (USA)
www.youtube.com (search for MS Learn Online: Understanding exacerbations)

MS and me: A self-management guide to living with MS

MS Trust (UK)
www.mstrust.org.uk

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