

Information for people living with multiple sclerosis

Symptoms

Heat sensitivity

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Many people living with multiple sclerosis find that heat can make their symptoms worse – which symptom and the severity varies from person to person. While it's common to experience a flareup of symptoms when hot, the effect is temporary and should calm down when you're cool again. With the right information and support, heat issues can be minimised or managed effectively to maintain a healthy and active lifestyle.

Multiple sclerosis and heat sensitivity

People living with multiple sclerosis often experience a reaction to heat (or increased heat) and a buildup of symptoms as a result. Depending on your situation, you may notice an increase in such things as fatigue, blurred vision, loss of balance or a flare up of problems with concentration, memory or other cognitive symptoms.

If you've had symptom changes like some of the more common ones mentioned above (or others), on a hot day, during exercise or in an overheated space, you're not alone. Keep in mind that this will pass – the effects of heat don't cause permanent damage to nerves and you should feel better once cool.

You might also experience heat sensitivity with colds, flu or other infections that cause a rise in body temperature, if stressed, while taking a hot bath or shower, visiting or moving to a hot climate. Some people even feel like they're having a relapse.

The Australian heat causes difficulty for people living with multiple sclerosis, and in some places the temperature can fluctuate from day to day. Remember that symptoms subside as your body temperature decreases, so it's good to find ways to keep cool.

What causes heat sensitivity?

There are several possible reasons. In many people living with multiple sclerosis, getting hot slows down the messages passing along nerves which have already been damaged by multiple sclerosis and this gives rise to increased symptoms. In some cases, there is a lesion in a part of the brain that controls temperature regulation in the body. Other people might have a lesion in a brain area that should respond to increased temperature, for example, by initiating sweating or sending more blood to the skin so you cool down again. In both cases, the poor response means that body temperature rises.

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What should I do if I experience heat issues?

If you have heat sensitivity issues and/or a worsening of symptoms talk to your MS nurse or GP, and at your next visit, tell your neurologist.

With the right advice, you can minimise or manage the effects of heat sensitivity.

The symptoms are generally quickly reversed when body temperature returns to normal, but some people living with multiple sclerosis find that a decrease in temperature also causes a worsening of symptoms. Like multiple sclerosis, reactions to heat vary from person to person, so an individual approach is best.

What can I do to manage this symptom?

Managing heat sensitivity

If you find the summer months difficult or your symptoms flare up due to heat, the following tips may be useful. Cooling down before, during or after activity can help to reduce the effects of heat. Cooling techniques can range from cheap and simple ideas to more expensive equipment items.

Tips to beat the summer heat

Personal cooling:

- Cool your body from the outside clothing, find shade, monitor your temperature, use body cooling sprays or other products.
- Cool your insides and stay hydrated drink fluids, especially water, but limit caffeine which can interfere with sleep and increase fatigue.
- If you're on the move avoid direct hot sun, rest during hot temperatures, park under cover or if outdoors, use a windscreen shield, call ahead to destinations about air conditioning or consider shopping online or using a delivery service.
- Exercise choose a cool or shady environment, exercise gently and rest often. Pre-cool yourself with cold drinks or a cold shower, or spray yourself with cool water.

- Clothing wear lightweight, loose clothing (light colours can also help) and hats.
- Mister spray or cooling gel in wristbands or scarves (during activities).
- Cool bath or shower or using a cooling suit (before activity) can give you more energy.
- Have regular cold drinks or suck an ice cube, icy pole or frozen fruit chunks.
- Spray your face and wrists with water from a plant mister (or commercial spray for personal cooling available from most chemists that will stay cool throughout the day).
- Some people find eating makes them warmer, and prefer salads or other cold meals and/or sip iced water while eating.



Keeping your environment cool:

- Keep your home cool use a fan, air conditioner or evaporative cooler. (For information about potential support for your energy bills, visit the EnergyAustralia website below).
- Turn central heating down or off.
- When you take a bath or shower, preferably start with tepid water.
- A floor or desk fan can help to keep the temperature down and the air flowing in a room.
 A handheld fan can be useful when moving around.
- Close curtains or blinds to help keep rooms cool.

Cooling garments

Cooling suits involve the user sitting next to a device that pumps coolant around the garment. While these are very effective at reducing temperature, they are not portable and are also quite expensive.

A less expensive option is special scarves, ties and wrist bands with a pre-cooled gel or other substance. The cooling effect can last from a few hours to several days.

Cool vests incorporate cooling packs fitted into the lining of a waistcoat-like garment, keeping the torso cool.

A large, foam filled cool pad called the Chillow can be used as a pillow or a cushion (available online and at selected chemists).

You may need to try a range of different options (or several at once) to find what works best for you.

Multiple sclerosis and cold sensitivity

Some people living with multiple sclerosis find that cold or cool temperatures (such as a light breeze or rain shower) make their symptoms worse. The effect is temporary and, when you warm up, the symptoms should go back to their usual level.

Sensitivity to cold is not as well known as heat sensitivity, but both occur quite frequently in multiple sclerosis. Some people are sensitive to both heat and cold, so the temperature needs to be just right for them to feel at their best. It can be hard to explain to others if heat makes some of your symptoms worse, but cold makes different symptoms worse. This is another example of everyone living with multiple sclerosis being different.

Which symptoms get worse?

Probably any of your symptoms can get worse. It's a very individual thing. The more common ones seem to be:

• Different types of nerve pain and sensory symptoms like numbness or tingling, which may be more troublesome.

- Mobility difficulties caused by muscle stiffness (spasticity) and spasms which can worsen.
- Fatigue and depression, although they may be more closely linked to lack of sunlight than the cold.

Why does it happen?

Like heat sensitivity, there are several possible reasons. In many people living with multiple sclerosis, getting cold also may affect the speed that messages pass along nerves which have already been damaged by multiple sclerosis, and this gives rise to increased symptoms. Sometimes, there is a lesion in a part of the brain that controls body temperature regulation. Other people might have a lesion in a brain area that should respond to decreased temperature, for example, by initiating shivering so that you warm up again. Without this response, you still feel cold.



What can I do if cold sensitivity affects me?

- Layers of clothes work well to keep your temperature just right. Try thermal socks, underwear, gloves, hat, scarves and coats.
- Hot water bottles, electric blankets and heat pads can work well but be careful if multiple sclerosis has changed how you feel temperature on the skin, so that you don't get burnt.
- Move around to improve your circulation and minimise muscle stiffness brought on by the cold.
 If you are sitting for long periods, try a blanket – some even have sleeves!
- Have hot food and drinks. Avoid too much alcohol which, although it can make you feel warm, increases blood flow to the skin and cools you even more.

Keep your home warm by closing curtains

- Keep your home well insulated and warm by closing windows, doors and curtains.
- Turn up the heating if you can (check out the EnergyAustralia website below for potential support for your energy bills).



General information and assistance

There is support available to help you manage your multiple sclerosis:

- Contact your state MS organisation (details below) to access services such as MS nurses, peer support and other resources.
- Speak to your neurologist and other healthcare providers about the best approach to treatment management for your individual circumstances.
- For information about multiple sclerosis and multiple sclerosis treatments, visit **www.msplus.org.au**

State MS organisations

MS Plus (Victoria, NSW, ACT and Tasmania)



1800 042 138 connect@msplus.org.au www.msplus.org.au

MSWA (Western Australia)



1300 097 989 communications@mswa.org.au www.mswa.org.au

MS Society SA & NT (South Australia and NT)



1800 812 311 msassist@ms.asn.au www.ms.asn.au

MS Queensland



1800 177 591 info@msqld.org.au www.msqld.org.au

Other organisations

The following support and utility services may be able to provide other advice:

Independent Living Centres 1300 885 886

www.ilcaustralia.org.au

Products to assist with your thermal regulation including special footwear, cool and heat mattress covers and body coolers.

Carers Australia 1800 242 636

www.carersaustralia.com.au

Provides information and advice to carers,

Sources

This fact sheet comprises material from previously published Australian MS organisation leaflets plus Multiple Sclerosis (MS) UK Trust online resources. The Brain Health Guide (and associated references), and has been endorsed by a medical expert, an MS Nurse and a person living with multiple sclerosis. their friends and families about carer support and services.

EnergyAustralia 133 466

www.energyaustralia.com.au/home/bills-andaccounts/concessions

Has information about concessions and/ or rebates offered by some state/territory governments to eligible participants, including for medical cooling and heating.

Disclaimer

Information prepared by MS Australia. It is intended to provide useful and accurate information of a general nature and is not a substitute for medical advice.