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MULTIPLE
SCLEROSIS
AND
VISUAL
PROBLEMS

2ND EDITION

ms.

Multiple Sclerosis Society of New Zealand

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Adapted from the older edition, *MS and Visual Problems: A Guide to Management*.

ACKNOWLEDGEMENTS

Our thanks to the MSSNZ Information Series Review Team.

MS and Visual Problems: 2nd edition published in 2007 by the Multiple Sclerosis Society of NZ with the support of the James Searle Say Foundation.

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ISSN: 1176-4473

ISBN: 978-0-908982-11-0

INTRODUCTION

Visual problems in MS are common, but they often clear up, with or without medication. A small number of people develop a persistent problem, but it is not usually severe.

This booklet discusses some of the basic facts about common eye problems that occur in MS, what help is available to you as well as what you can do to help yourself.

A problem with vision may be caused by a number of factors; it is important not to assume that all difficulties are due to MS. If you develop problems with your vision, ask your GP for a referral to an ophthalmologist (eye specialist) or neurologist. Seek advice on what might be causing it and what might be done.

If you wore glasses before your MS diagnosis, eye specialists recommend you continue to visit your optometrist or ophthalmologist regularly.

COMMON VISUAL PROBLEMS IN MS

There are several:

- Blurred vision (in one or both eyes), often with eye pain (optic neuritis).
- Double vision (diplopia).
- Movement/instability of vision.
- Transient blurred vision during exercise or in a hot environment (Uhthoff's symptom).

OPTIC NEURITIS

Optic neuritis is inflammation of the optic nerve. It is a relatively common first symptom of MS, but not all people who have optic neuritis get MS.

Effect on vision

Symptoms vary widely in severity, but typically it develops as pain and blurred vision over several days. The pain is usually a dull ache in and behind the eye and at times is severe. Typically, the pain is worse on eye movement. There may be tenderness when the eye is touched.

The blurred vision is often described as a black spot in the middle of the vision (e.g. the centre of someone's face might look blurred and the outline clearer). Some people find this can be made worse

by heat, exercise, being in bright surroundings or following prolonged fixation of gaze.

People also describe colours breaking up, seeming dull or 'washed out' in the affected eye (i.e. a reduction in colour vividness, particularly for reds).

Some subtle changes related to colour contrasts and clarity of vision may be difficult to detect on standard tests of vision.

Visual flashing sensations brought about by eye movement or sound often occur with optic neuritis. They are most obvious in a dimly lit room. Worse vision in bright light is another common symptom. It is likely that these symptoms are caused by fluctuating interference of the nerve transmissions along the visual pathways.

It is rare for both eyes to be affected together. However, when one of the eyes is affected, there can be interference between the picture seen by the 'normal eye' and the other imperfect eye.

How is optic neuritis diagnosed?

Doctors will diagnose optic neuritis by asking about a person's history and observing typical signs. Through an ophthalmoscope, swelling of the optic disc (the area where the optic nerve attaches to the eyeball) may be observed. Later, even if there is good recovery of vision, the optic disc may become pale (optic atrophy).

Tests of the speed at which nerve impulses travel in the optic nerves (visual evoked potentials) are a sensitive measure of current or past

optic nerve damage. Magnetic resonance imaging (MRI) scans may show active inflammation of the optic nerves.

Management

As with other types of MS relapse, corticosteroids are used for the treatment of optic neuritis, particularly if visual impairment is moderate or severe or is interfering with daily function (e.g. mild impairment may be limiting for people in some occupations). Steroids also reduce eye pain.

While steroids have been shown to shorten recovery time after a relapse, they do not appear to influence the final extent of recovery of vision. They are given in high doses orally or by intravenous infusion.

Recovery from optic neuritis

Most recover well from optic neuritis, but full recovery often takes weeks or months. Signs of improvement are usual within three weeks and in 90% of cases essentially normal vision will return within eight weeks of an attack. Further improvement in vision can still occur up to a year or more after symptoms begin.

DOUBLE VISION

Double vision or diplopia is a fairly common symptom of MS. It occurs when inflammation in the brainstem causes interference with the nerve control of the eye muscles. The lack of coordination of movements means the eyes do not focus together meaning that the image focuses in different areas of the retina in each of your eyes, too far apart for your brain to merge them. This results in seeing

double. The double images may be side by side, one above the other or slanted.

Double vision is often associated with other symptoms such as impaired balance with giddiness or vertigo. Recovery is usually good over weeks or months.

Management

Steroids are often used to treat diplopia as the symptoms are very disturbing. Again, the evidence is that they speed the rate of recovery, but may not affect the extent of long term recovery.

Double vision goes away when you cover one eye. This is not recommended for long periods, but useful for driving and performing short tasks, so the wearing of an eye-patch over one eye can alleviate the problem. It makes little difference which eye you cover, if vision in each eye is normal, but the range of movement may be more limited in one eye. Covering each eye alternately may be tried.

If diplopia is stable and persistent an eye specialist can prescribe glasses with prisms which may relieve the symptom.

MOVEMENT/INSTABILITY OF VISION

This is a less common visual disturbance, also due to brainstem inflammation, which may be accompanied by diplopia. There is a sense of movement, often jerky, of the environment (oscillopsia) and difficulty focusing, usually with instability while walking. Underlying it is a failure of the mechanism that holds the eyes stable.

An observer usually sees persistent jerky eye movements (nystagmus) which are most often up and down or slanted. However, visible nystagmus is not always associated with symptoms that the patient notices, especially when it is from side to side and present only when looking to one side.

Management

Unfortunately, although there may be some improvement with time, instability of vision may be a persistent problem that is difficult to treat. It may be worse in some head positions, so tipping the head forward or back may help to some extent.

Drugs such as clonazepam and gabapentin can occasionally help, but side-effects are often limiting. Diaminopyridine has recently been suggested, but is not readily available. There is possibly a place for muscle relaxant injections (botulinum) into the eye muscles.

Work is being done on optical devices to stabilise the 'wiggling' visual environment of people with oscillopsia. Special lenses with prisms can offer some relief, as can mounted magnifiers, largeprint books and a variety of other largeprint or high-contrast low-vision aids.

UHTHOFF'S SYNDROME

This is temporary blurring of vision during exercise or in a hot environment such as a spa bath. It was first noted by Wilhelm Uthoff, an ophthalmologist, in 1890 while studying people with MS. The blurring settles in a few minutes on stopping exercise or cooling down, but may occur repeatedly in the same circumstances.

This is a common symptom in MS and usually follows an attack

of optic neuritis, but occasionally may occur without preceding visual symptoms. The recurring symptoms do not indicate fresh inflammation or nerve damage, but are due to temporary impairment of electrical conduction in previously damaged and repaired nerve fibres.

Management

The symptom tends to gradually settle but may persist for months. Mild symptoms may not be limiting but they are frequently irritating. The only effective management is to reduce activities that bring on the symptoms.

LIVING WITH A VISUAL PROBLEM

MS is not a one-symptom condition. Often you can be so overwhelmed by other symptoms or disabilities that you do not see yourself as visually impaired. On the other hand, in the presence of other disabilities, a degree of visual impairment may seem more threatening.

If you do have substantial visual impairment, a good way to gain access to services is to become registered with the Royal New Zealand Foundation for the Blind, as partially sighted or blind.

They are extremely helpful and have many useful services—all available to people with MS and visual problems. (*See Sources of Support and Information on page 15*).

TIPS FOR BETTER LIVING WITH VISUAL IMPAIRMENT

When modifying your environment to better manage visual problems, you should consider:

- Contrast—the difference in the lightness or darkness of colours within an object or between objects, is essential for providing cues as to where an important object sits or where the edges of doors or steps are. Objects similar in brightness or darkness are very difficult to distinguish.
- Low-level lighting or general diffuse lighting can worsen the situation significantly. Use lamps that can aim the light right where it's needed. Try different types of lighting— incandescent and halogen work best. Fluorescent light produces glare. If you must use it, try energy saver bulbs or full colour spectrum bulbs. Eliminate glare by making sure that light cannot reflect off mirrors and shiny objects.
- Textures of different types can further define edges, buttons, controls and other objects within your environment. Masking tape, felt tape, Velcro—all provide easily identified textures.

SPECIFIC LIVING & COPING STRATEGIES

Out and about

- When travelling, pack a magnifying mirror, a magnifier, a clip-on book light, a night light and a small flashlight.
- Find out where the accessible toilet is whenever you are in an unfamiliar place.

- At the movies, take both a flashlight and a light coloured sweater. Put the sweater on your seat when/if you get up, to help you identify it when you get back.
- Tell new people you meet you don't have complete vision, so they won't think that you're rude if they wave and you don't respond.

At your desk

- Use adhesive-backed, large-print numbers and letters (called zoom caps) on your computer keys.
- Add lighting to your computer or desk.
- Re-label your files using a black ink on white file folders.
- Buy a phone with large numbers, a voice-activated phone or one with programmable numbers.
- Find out about low-vision computer enhancements.

In the kitchen

- Pare down what you have in your cabinets and shelves.
- Reorganise shelves, putting frequently-used items in the front.
- Label fridge & freezer shelves for easy retrieval.
- Buy drawer organisers in contrasting colours from the items you store in them.
- If your budget allows, have dishes and glasses in both a solid light colour and a solid dark colour and use with foods and beverages of the most colour contrast.
- Buy different light and dark coloured chopping boards to add contrast for easier chopping and slicing of food.
- Keep your fingertips curled under when slicing, or buy a pair of fish-cleaning steel-mesh gloves. They prevent cuts.
- Purchase measuring spoons and cups with large contrasting

numbers, or practice measuring directly into your hand.

- ➔ Mark often-used appliance settings with textured paint or a glued-on bead.
- ➔ Differentiate bottled foods from bottled cleaning products by using different, distinctive bottles.
- ➔ Before turning on the stove, place the pot on the element.
- ➔ Before reaching into a hot oven, use a fork or spoon to tap and feel where the rack is located.
- ➔ Long oven mitts offer burn protection.
- ➔ If possible, replace clear glass utensils with coloured ones that are easier to see.

Looking your best

- ➔ Have someone help you go through your closet and remove the things you don't wear. Then separate the rest by colour and develop a marking system.
- ➔ Hang belts, scarves, or neckties with the outfits they match.
- ➔ Sock and stocking colours can be identified by using a safety pin system: for black - no pins, brown - one pin, navy - two pins. Same for shoes, but mark the soles or insides with adhesive dots.
- ➔ For make-up, get an organiser and develop a colour coding system.
- ➔ In the shower, soap on a rope is helpful, or use a wash mitt with an opening for the soap so that you won't be dropping it and then having to find it. Put shampoo in a different bottle from the conditioner, so you know which you are using.

In bed at night

- ➔ Always turn your bedside light on before you get out of bed if you have to get up during the night.

FINAL THOUGHTS

Vision problems offer their own set of special challenges for people with MS who experience them. Fortunately, the prognosis for recovery from many vision problems associated with MS is good.

Understanding vision problems and what can be done about them is the key to being able to manage them. As with other MS-related symptoms, managing problems works best when you, your family, carers and other support services take a positive and collaborative approach.

Don't ignore vision problems when they arise—seek help and input from others who are there to help. There are ways to manage vision issues with help from others and good approaches for lessening their impact on your daily living.

You may need to put in extra effort to manage the difficulties you experience and modify your environment in simple, practical ways—so you can better cope with the way you do things in everyday life.

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.

ROYAL NZ FOUNDATION FOR THE BLIND

The Royal New Zealand Foundation for the Blind is extremely helpful and has many useful services and resources—all available to people with MS and visual problems.

Ring the Foundation's toll free number 0800 24 33 33 for assistance. The staff there will answer your queries about technological aids for vision problems, other equipment and resources.

You can also use the Foundation's Online Equipment Shop at <https://www.rnzfb.org.nz/equipmentshop> or their online library catalogue at <http://www.rnzfb.org.nz/library>. They have a collection of talking books and braille books for adults. Don't forget your local public library—it can supply talking books and large print books too.

Disability

Weka: *What Everyone Keeps Asking*—about disability

website www.weka.net.nz

phone 0800 17 1981

CONTACT DETAILS

THE MS SOCIETY OF NEW ZEALAND

MSNZ

PO Box 32124 Christchurch 8147 NEW ZEALAND

Phone 0800 MS LINE or 0800 675 463

Email info@msnz.org.nz

Website www.msnz.org.nz

REGIONAL MS SOCIETIES

Northland	09 438 3945	Manawatu	06 357 3188
Auckland	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	06 835 8542	South Canterbury	03 687 7375
Taranaki	06 751 2330	Otago	03 455 5894
Wanganui	06 345 2336	Southland	03 218 3975

OTHER SOURCES OF SUPPORT

weka: *What Everyone keeps Asking* - about disability
website www.weka.net.nz phone 0800 17 1981

Enable NZ

website www.enable.co.nz phone 0800 362 253

Carer's New Zealand - NZ's national organisation for carers

website www.carers.net.nz email info@carers.net.nz

phone 09 406 0412

ISSN: 1176-4473

ISBN: 978-0-908982-11-0

