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**MULTIPLE
SCLEROSIS
AND
CHANGES TO
THINKING &
MEMORY**

ms.

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AUTHOR

Written by Ron Dick, Neuropsychologist, Waikato Hospital.

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Multiple Sclerosis Society of New Zealand Incorporated
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

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INTRODUCTION

MS can sometimes affect a person's ability to think and remember. Common observations include:

“I find it very hard to concentrate”

“I often can't find the words I want to use”

“I have trouble remembering names of people”

The technical term for problems with thought processes is 'cognitive dysfunction' and whether a person with MS will experience these problems cannot be predicted from age, level of physical disability, duration of MS, type of MS, or intelligence tests.

Cognitive dysfunction is not necessarily progressive, and has no predictable onset or occurrence. It does not necessarily relate to physical disability and it is probable that only 10% of people with MS will have cognitive problems that significantly interfere with everyday activities.

This booklet was written for someone with MS, to provide a better understanding of the common problems with thinking and memory that can occur with MS. It explains some of the reasons for cognitive dysfunction, and suggests activities and resources that can help deal with the effects of these changes.

THINGS YOU SHOULD KNOW ABOUT MS

There are some common misunderstandings about cognitive problems related to MS. Some important assurances include:

MS does not equal Dementia

People with Alzheimers, for example, have difficulty storing information from moment to moment. People with MS tend to have a difficulty with retrieval of information.

MS does not mean that intelligence has declined

Although some people with MS may not be able to think as flexibly as they once did, intelligence itself tends to remain stable. Overall, people with MS experience only minor declines in intelligence. Only a small group (thought to be around 10%) experience cognitive dysfunction that is severe.

MS is not a mental illness

Some people with MS may have difficulties with specific thinking processes, but this is due to the nature of the disease process. Treatment and rehabilitation for cognitive dysfunction in people with MS is usually co-ordinated by medical (rather than mental health) services.

However, people with MS sometimes experience depression, and this requires medical and psychiatric treatment.

Cognitive functioning can be assessed

The cognitive status of a person with MS can be formally assessed using a series of tests administered by a neuropsychologist. If cognitive problems are impacting on work or study, then an assessment would generally be warranted.

Cognitive problems can occur at any level of physical disability

People with MS who are severely disabled physically may have no cognitive problems, while those who may exhibit few physical symptoms may have a number of cognitive problems. There is no clear link between either disease severity or duration and cognitive dysfunction.

HOW DOES MS AFFECT BRAIN FUNCTION?

In MS, inflammation and scarring damage nerve fibres and interfere with the transmission of messages from one part of the brain to another.

When inflammation disrupts the messages relating to important motor or sensory actions the effects are likely to be immediately obvious, although they vary from person to person. Damage to less significant parts of the brain will still cause problems, but may be more subtle, and take longer to be noticed.

Common MS-related problems with cognitive functions include:

Attention span might be affected. *“I can’t concentrate like I used to”. “If I am doing any one thing for too long I lose focus”.* This is also called “mental fatigue”.

Speed of processing of information might be affected. *“My processing is significantly decreased, and this frustrates me”. “I am a lot slower in my thinking now”.*

Memory might be affected. *“If I don’t write things down I forget them”. “I forget things I am told, sometimes within seconds”.*

Ability to **solve problems**, to **reason** and to **plan** might be affected. *“I find it very hard to think logically to make a decision”. “I do worry sometimes that I have problems with logical thinking”.*

The **ability to see objects ‘in space’** might be affected. *“I have to be careful when I reach for objects as I can’t judge where they are the same as I used to be able to”. “I have had to stop driving because I was having difficulty judging distances”.*

Language might be affected. *“I don’t have the fluency I used to have when talking”. “I can’t find the words that I want to use, although I know what I want to say”.*

Note: Not all cognitive dysfunction is a direct result of damage within the nervous system. It can have a number of other causes, including occurring as part of a person’s natural ageing process. Thus, it is very important to advise your doctor about any difficulties you are experiencing, so they can be investigated and the appropriate treatment used.

Many factors will determine your response to cognitive problems, including the impact of the disability on your normal way of life, previous ways of coping, and the support you receive from others.

Carers and family members should also note any changes to cognitive functioning in people with MS. Changes should be discussed with the person with MS, and referred to a medical professional if there is any concern.

MULTIPLE SCLEROSIS & EMPLOYMENT ISSUES

Although MS can affect your ability to work, staying employed for as long as possible is important. It may be necessary to make changes to the job or to be re-deployed within the work environment where your skills, expertise and experience can be used. As long as you are able to manage your responsibilities, or can be re-deployed to an area more suited to your symptoms and abilities, then continuing to work is to be encouraged.

Admittedly, some jobs may no longer be suitable if you have cognitive problems (or physical problems like impaired balance). Involvement in volunteer work can be a good alternative and there are many organisations looking for help. It may be that early 'retirement' is the only option.

If you do stop working, the transition from being employed to not being employed should be planned carefully. It is a good idea to consider involving your employer, your GP, and an MS Society field officer in the process. It may also pay to speak to Work and Income—especially as the principal income earner in your family (see page 14 for contact details).

GETTING HELP WITH COGNITIVE PROBLEMS

Cognitive dysfunction is best managed by learning new and different ways of dealing with any problem areas. Often input is needed from a professional trained to assess and treat people with cognitive problems. The health professionals who can help are neuropsychologists, occupational therapists, and speech language therapists.

Neuropsychologists understand the relationship between brain functioning and behaviour. They assess brain functioning and can recommend treatment programmes for many of the affective (emotional) and cognitive (thinking and memory) disturbances associated with MS.

Occupational therapists can help with learning compensatory strategies for the workplace and at home. It is important to involve a professional early to ensure independence (and employment) for as long as possible.

Speech and language therapists provide assessment and assistance for communication problems, as well as other MS-related issues such as swallowing and saliva management.

As the impact of cognitive changes can be stressful, it may also be helpful to talk to a counsellor or your doctor about how you are feeling.

PRACTICAL IDEAS FOR COGNITIVE PROBLEMS

IDEAS FOR MANAGING MEMORY PROBLEMS

It might help to get an 'organiser'. Set it up with sections for everything that affects your day-to-day living. Sections for appointments, for phone numbers, addresses etc. Anything that you need to remember.

Keeping to a routine is important, as is being consistent. For example, when you open the door to your house, put your keys in the same place every time, so you will always know where to find them. Setting routines also helps with the completion of tasks.

Using mental pictures or images to remember something can be a good technique to aid memory. For example, to remember a dentist appointment, in addition to writing the appointment in your daily schedule planner, picture a giant tooth with a giant drill, and a giant of a dentist hovering over it. Mental imagery can also be used when trying to remember a person's name, by focussing on some particular feature of the person.

Having people repeat or write down instructions often helps. It is important that the person conveying the message, instructions or directions to you knows that you have understood. Repeat it back to the person, and ask for clarification if necessary.

Keep your mind as active as possible. Reading, doing crosswords and puzzles are good ways of keeping mentally challenged, and it is best to find activities that suit you. However, you do need to be aware of your energy levels and be careful not to tire yourself out.

IDEAS FOR MANAGING FATIGUE

Regular rests to recharge your brain (and body) become important when you have MS. Use energy conservation and work simplification techniques to ensure the best possible use of your physical and mental energy. Be aware of and alert for mental fatigue (a decline in cognitive performance following a task requiring continuous mental effort).

If fatigue is an issue for you, occupational therapists can offer strategies to help you to manage both physical and cognitive fatigue. It is also best to avoid noisy and/or distracting environments as these can make it difficult to concentrate.

It is also important when learning a new task that you allow plenty of time to learn it. If you are having trouble, shift your attention to another task and come back to it later.

OTHER COPING STRATEGIES

Having MS may mean that you are less responsive to feedback from others and find it harder to adapt to changes in routines or the environment. Information gathering, planning, and goal setting will help.

Positive reframing, (looking at your situation in a positive way) is a useful approach. Benefits from positive reframing include improved family relations, increased compassion and enhanced appreciation of life.

Information on the effects of cognitive changes due to MS can be obtained several ways: publications such as this booklet, books at your local library, resources from local and international MS Societies, other people with MS, or by seeking help from professionals.

It is important that you know that you are not going crazy, that many people with MS experience similar problems with their thinking and memory.

In particular, it is important for friends and family members to be aware of the relationship between MS and cognitive dysfunction. This will help them understand what you are going through, how having MS is affecting you, and that it is the MS that is causing your difficulties. Knowledge, understanding and communication are essential for everyone.

Depression and anxiety can also affect concentration and information processing, and may need specific treatment.

FINDING SUPPORT FOR COGNITIVE PROBLEMS

Your doctor is your main health care provider, so it's important to communicate your worries and symptoms as clearly as possible to ensure appropriate assistance.

The following information and referrals are available from your doctor. These are invaluable sources of help, supplies, and government funding should you require their services. Not only are they very important; they're completely free.

COMMUNITY OCCUPATIONAL THERAPIST

A Community OT knows how to access funding from regional agencies for aids such as handrails or tools for ease of living and safety around the home. They are able to submit applications for mobility aids and make referrals to Disability Support Link (DSL) who assess and fund personal care and housekeeping hours.

COMMUNITY PHYSIOTHERAPIST

A community physiotherapist is available to provide home visits to help with issues relating to physical limitations. They can advise on exercises and ways of reducing the strain on weakening muscles.

Referrals to speech therapists, neuropsychologists, and any other support services, can also be accessed through your doctor.

SOURCES OF SUPPORT AND INFORMATION

THE MS SOCIETY OF NEW ZEALAND

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

INTERNET RESOURCES

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

MS SOCIETIES

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

DISABILITY

Weka: *What Everyone Keeps Asking*—about disability
website www.weka.net.nz
phone 0800 17 1981

CONTACT DETAILS

THE MS SOCIETY OF NZ

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

MSNZ

PO Box 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 & North Shore	09 845 5921	Wellington	04 388 8127
Waikato	07 834 4740	Marlborough	03 578 4058
Bay of Plenty	07 571 6898	Nelson	03 544 6386
Rotorua	07 346 1830	West Coast	03 768 7007
Gisborne	06 868 8842	Canterbury	03 366 2857
Hawkes Bay	06 835 8542	South Canterbury	03 687 7375
Taranaki	06 751 2330	Otago	03 455 5894
Wanganui	06 345 2336	Southland	03 218 3975



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