



Welcome to todays Webinar

Presenter: Dr Ben Harris
Facilitator: Chris Porter



Acknowledgement



We acknowledge and pay respect to the traditional custodians past and present on whose lands we meet today.

We acknowledge the deep feelings of attachment and the relationship of Aboriginal people to country and respect the cultural authority of the elders in each community

Informed Choice



This presentation has been prepared and is presented by an independent expert.

The views presented are not necessarily the views of Multiple Sclerosis Limited.

Individuals should seek further advice regarding relevance for their situation.

Multiple Sclerosis Limited

Everyday Strategies to Manage Thinking and Memory Changes Associated with MS

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Overview

- Brief summary of areas of cognitive function commonly affected by MS
- Rationale for using strategies to assist with daily functioning
- Presentation of strategy options directed towards managing specific cognitive problems
- Aim is to present general information that can be applied or adapted by an individual based on their personal circumstances

Rationale for using strategies

- Presently there are no medications that have been shown to improve cognition in MS
- Currently no evidence that 'brain training' programs provide benefits to everyday cognitive functioning in people with MS
- No evidence to support idea that memory is equivalent to a mental muscle that can be strengthened by memory drills

Rationale for using strategies

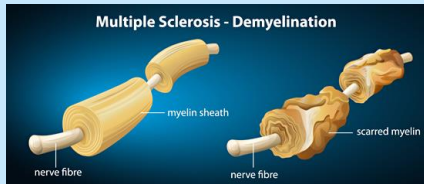
- Using strategies will not make your memory or other cognitive processes worse
- By contrast, effective use of strategies generally results in better organisation, so available memory resources are used more efficiently
- MS is a disease of the central nervous system that causes cognitive change for many people, so adoption of strategies is the most effective way to improve functioning

Targeting strategies

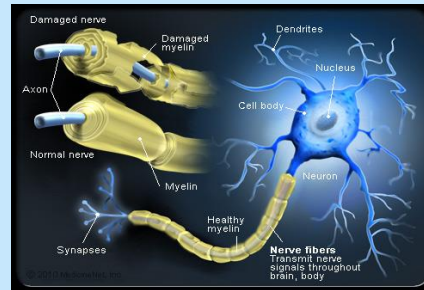
- Can be difficult to know which strategies to use without knowing a person's individual cognitive strengths and weaknesses
- Role of neuropsychological assessment to establish this pattern can allow for more targeted management
- Certain cognitive problems are more prevalent in MS so will be the focus today

MS and myelin

Inflammation leads to demyelination

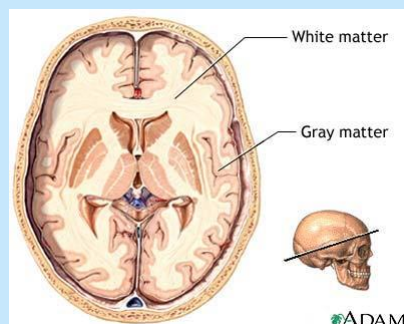


Demyelination leads to transmission problems within the brain



White matter

- The way in which information is taken from one neuron to another
- MS is a disease of the white matter, so tends to affect cognitive processes that particularly rely on effective communication between multiple areas of the brain



Processing Speed

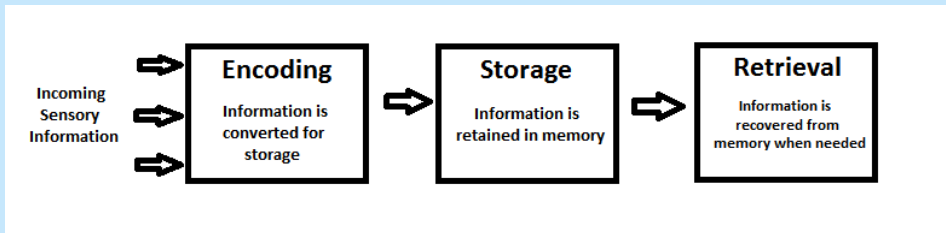
- Slowed of processing can be associated with:
 - difficulty keeping up with conversations
 - difficulty understanding instructions
 - difficulty learning new tasks
 - needing longer to complete tasks
 - inefficient memory for new information

Attention

- As with reduced processing speed, problems with attention result in:
 - difficulty focusing on conversations
 - difficulty filtering out unwanted information
 - difficulty with 'prospective' memory, i.e. remembering to remember something later on
 - inefficient memory for new information
- Fatigue is known to majorly impact complex attention abilities

Memory

- 3 stages to effectively remembering something:



Executive Functions

- 'Executive function' is an umbrella term that includes:
 - problem-solving
 - planning and organising
 - initiating behaviour
 - self-monitoring performance
 - self-correcting and thinking flexibly
 - reflecting

General approach to cognitive strategies

- Best to develop an individualised approach which depends on:
 - the strength and types of cognitive problem being experienced
 - what the individual is trying to achieve
- ‘Internal’ memory strategies include making up rhymes and mnemonics but generally have limited usefulness because they are mentally demanding to put into practice

General approach to cognitive strategies

- Better off using ‘external’ memory strategies, i.e. memory aids, written systems, etc.
- The best strategies will be ones that make sense to you and are designed to help with specific problems being experienced
- Most people without any identified memory problems use specific strategies (e.g. diary, shopping list)

Fatigue

- Everyone experiences cognitive inefficiency when fatigued
- A particular problem for people with MS – reported to be the most common symptom, i.e. affecting over 90% of people
- Important to acknowledge this symptom and make allowances:
 - reduce commitments to a manageable level
 - allow regular breaks
- Important to pace yourself

Fatigue

- Be aware of what is in your schedule and allow sufficient time, i.e. preparation time, travel time, activity time, rest time
- Organise to complete more complex tasks at times of the day when fatigue is less likely, i.e. in the morning, after a break
- Monitor for times of day when commonly fatigued and try to plan breaks or less demanding activities then
- Try not to compromise on planned breaks, i.e. these are essential to optimal functioning and not a sign of laziness

Attention and processing speed

- The white matter changes in MS can reduce a person's capacity to pay attention and process information efficiently, i.e. it is not a matter of effort
- Problems with attention and speed act as a bottleneck that affect subsequent processes, such as memory

Attention and processing speed



"You don't mind distractions as much as me, so I didn't think you'd mind if my kids played in your office today."

Everyday situations can be full of distractions:

- Television
- Radio
- Emails
- Background conversations
- Children
- Worries/thoughts

Attention and processing speed

- Strategies:
 - turn off distracting devices when needing to concentrate
 - ask people to repeat information or simplify
 - write things down:
 - opportunity to re-process information and there to see later
 - carry a notebook or diary at all times and develop a habit of using it regularly, even for incidental information
 - try not to rush (so plan ahead) and better to stop and calm self down if flustered, rather than rushing on and making mistakes

Memory strategies

- When considering strategies to support memory, the following is important:
 - strategies need to be quick and easy to use
 - strategies need to apply directly to the task or problem they are meant to help
 - where possible, strategies should be consistent with habits a person already has
 - the person needs to be committed and motivated to use the strategies
 - it may be necessary to involve family members or co-workers, at least initially

Memory strategies

- Remembering what people say:
 - this information is easy to forget because it is often rapid and you may be distracted or tired
 - keep a notepad by the phone at home or in a central location at home if you use a mobile
 - when out, carry a notebook in your purse or pocket
 - when a conversation has occurred, write down a few brief points or key words to jog your memory later on
 - for more complex or lengthy conversations, consider using a dictaphone as back up for written notes

Memory strategies

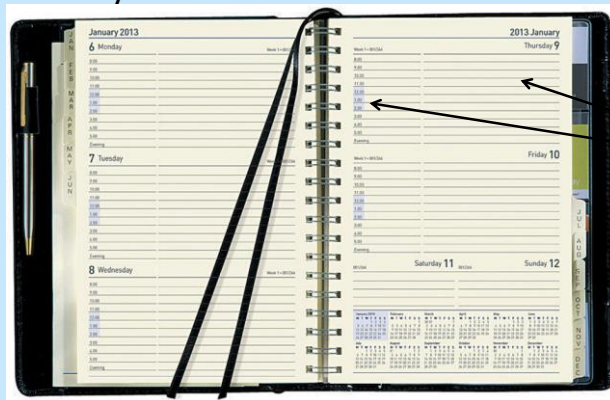
- Remembering what needs to be done:
 - Need to select a system that meets your needs
 - Calendar for upcoming events and appointments, kept in a central location and all family members encouraged to write events on



Ensure that calendar format allows enough room to include required information

Memory strategies

- Remembering what needs to be done:
- Use of a paper diary – updated regularly and taken everywhere



Contains times for events and a space for additional notes

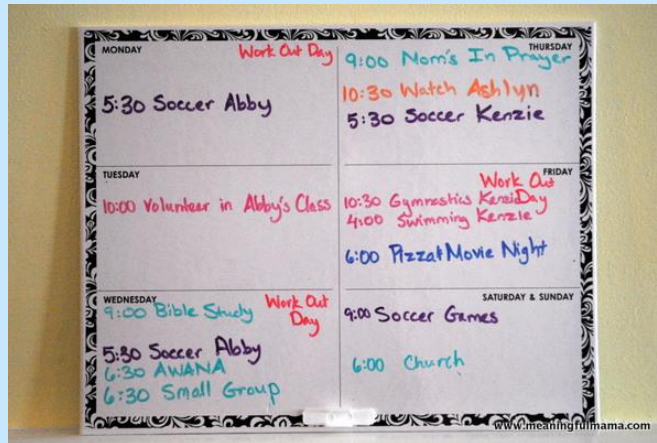
Memory strategies

- Remembering what needs to be done:
- Electronic diaries – have the advantage of inbuilt alarms



Memory strategies

- Remembering what needs to be done:
- Whiteboard



Memory strategies

- Remembering what needs to be done:
 - it is better to use a simple, well-organised system
 - using multiple notebooks, diaries, calendars create opportunities for error
 - need to develop a rigid habit of checking the memory system in a regular fashion, preferably first thing in morning and last thing at night (use of alarm to prompt)
 - consistent information transfer between systems, e.g. from notebook to diary

Memory strategies

- Remembering what to buy/what to take:
 - notes can be a good way to prompt your memory quickly
 - leave Post-it notes in a prominent position (e.g. the inside of the front door) to remind you which items to take when you leave
 - if you need to take something with you the following day, leave it next to the front door or on the seat of your car

Memory strategies

- Remembering what to buy/what to take:

SHOPPING LIST			
carrots	chicken	cheese	bread
beans	bacon	milk	jam
potatoes	beef	eggs	spaghetti
tomatoes	ham	yoghurt	muesli
bananas		ice cream	corn flakes
apples		butter	flour
strawberries			chocolate
lemons			

Shopping lists:

- Prominent position in kitchen
- Immediately add items as run out
- Group items by category
- Cross off items in the shop
- Pre-printed computerised list of regular items
- Consider online shopping

Memory strategies

- Remembering where things are:
 - people often spend time and energy looking for things, e.g. glasses
 - try and reduce clutter on surfaces
 - have a single place (e.g. a dish) where you routinely deposit items (e.g. keys, wallet, phone) upon returning home
 - once a system is in place, be diligent about returning items to where they belong – developing a consistent habit is important

Executive-level strategies

- Problems with higher-level thinking processes can manifest in a number of ways and make difficult the completion of complex or non-routine tasks
- Problems include disorganisation, becoming side-tracked, distractibility, confusion about what to do next, problems initiating
- Important to manage expectations of self and others – may need to complete fewer tasks, be given extra time, or complete a simpler version of the same task
- Tasks can be broken down into component parts which can then be completed sequentially

Executive-level strategies

- Example of breaking down a complex process – getting kids to school and self to work

• Shower/dress self	7.00am	<input type="checkbox"/>
• Kids up and dressed	7.15am	<input type="checkbox"/>
• Breakfast	7.30am	<input type="checkbox"/>
• Make lunches	7.45am	<input type="checkbox"/>
• Pack school/work bags	8.00am	<input type="checkbox"/>
• Clean teeth/final check	8.10am	<input type="checkbox"/>
• Leave for school	8.30am	<input type="checkbox"/>
• Arrive at work	9.00am	<input type="checkbox"/>

- Important to complete a stage once started
- Use of verbal prompts, e.g. “what comes next?”
- Allow sufficient time to complete each step
- Practice until routine and need for external prompting reduces

Case example of strategy use

- Julie has been worked in an office for the past 3 years but has recently noticed changes to her cognitive functions and become aware of the following problems at work:
 - increasingly fatigued by mid-afternoon
 - difficulty concentrating in open-planned office
 - forgetting to follow-up assigned tasks
 - poor recall for conversations in meetings
 - difficulty learning a new email system

Case example of strategy use

- Where possible, useful to discuss issues with management to determine scope for flexibility
- Fatigue management:
 - build in regular 15-minute breaks in which a quiet, solitary activity occurs
 - where possible, have meetings at the beginning of the day or following a break
 - possibly adjust working hours

Case example of strategy use

- Management of distraction:
 - open planned office is large and noisy in her section – neighbouring colleague makes numerous phone calls and regularly plays music at desk
 - relocated to a corner of the office where neighbouring colleagues mainly use computer rather than phone
 - continued checking of email distracts from other tasks
 - set aside two periods of time per day where emails are checked and responded to
 - phone set to voicemail at times when more complex work being done to avoid distraction
 - work areas kept free from unnecessary clutter

Case example of strategy use

- Forgetting to follow up on tasks:
 - more efficient use of a diary
 - introduction of a *to do* list which is written on a different coloured piece of paper to stand out
 - *to do* list prepared at the start of each day with items listed in order of priority
 - information from diary and email transferred to list
 - items crossed from *to do* list once they are completed

Case example of strategy use

- Reduced recall of conversations from meetings:
 - agreement with colleagues that brief minutes kept which highlight action needing to be taken
 - colleagues to flag with Julie if they are commencing discussion of an issue to which she needs to pay particular attention
 - more complex information pertaining to Julie able to be tape recorded by her to allow subsequent review if necessary

Case example of strategy use

- Mastery of new email system:
 - time allotted where Julie shown new features in depth by a colleague
 - Julie to take written notes, have the opportunity to practice, and subsequent trouble shooting sessions available with the colleague
 - instructions made practical and simple to understand

Impact by stress and distress

- Evidence from mild brain injury research that the degree to which an individual complains of functional problems is more closely related to their subjective level of distress than it is to measures of their cognitive problems
- Highlights the complex interaction between cognitive and emotional problems and the way in which a person functions
- MS frequently first occurs when people are young, so may still be studying, establishing vocational skills, so challenging to compensate

Impact by stress and distress

- Can be great stress associated with physical and cognitive changes which can lead to problems with self-esteem, depression, anxiety, loss of roles, etc.
- Feelings of not coping can lead to anxiety, distress, insecurity, low mood
- These types of psychological difficulties can further impact the types of cognitive change seen in MS which can then exacerbate the situation further
- There is good evidence for the efficacy of psychiatric and psychological intervention in improving these problems

Neuropsychological Assessment/Intervention

- Role of a neuropsychologist is to:
 - assess cognition and behaviour in a sensitive and standardised way
 - interpret the results in terms of an individual's strengths and weaknesses
 - use this pattern of results to help work out strategies to assist with activities in daily life that are being experienced as difficult

Accessing help from MS

- If changes to cognition seem to be impacting important areas in your life, contact MS about options for assessment and assistance
- Occupational therapists are skilled at helping implement strategies that can improve a person's functioning
- Psychological assistance is available in the community

Questions



MS Connect

1800 042 138

msconnect@ms.org.au

Library & Publications



In the [Library & Publications](#) section of our website you can find information about:

- MS Library services
- How to borrow both eBooks and print books on topics such as wellness, and managing multiple sclerosis and its symptoms
- Accessing our online library catalogue
- MS publications, including *Intouch* magazine, email newsletters, booklets and information sheets

Visit our website for more information www.ms.org.au

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Library & Publications



Library & Publications

The MS Library service is available to people with MS, their families, carers, health professionals and anyone with an interest in MS within the AUST, NZ and Victoria.

The MS Library collection includes eBooks, print books and DVDs about managing MS and its symptoms, nutrition, exercise, self-management, chronic illness and wellness.

Library staff can recommend relevant resources, both from the library collection and also resources freely available online from reliable sources. Information can be sent out by email and post.

MS Library catalogue

Our online catalogue is accessible here.

You don't need to log in to search the library catalog but logging in makes it possible to change your password, update your contact details and review loans. Please email library@ms.org.au as library staff to request login details for the catalogue.

Accessing MS Library eBooks

The MS Library has a small but growing eBook collection, which can be accessed with login details for EBSCOhost (our eBook provider). Please email library@ms.org.au to request these details and further information about accessing our eBook collection.

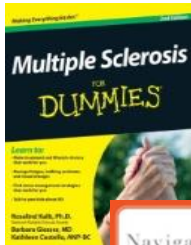
Borrowing print books/DVDs

There are two ways to request print resources/DVDs from the MS Library.

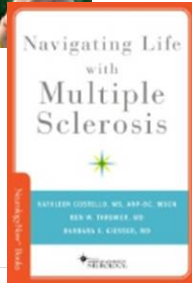
1. Once logged in on the **library catalogue**, place an item on hold. This will generate an automatic email to library staff who will let you know if the item is available.
2. Email library@ms.org.au with information about the resource you would like to borrow or the topic you are interested in, and library staff will let you know if relevant items are available.

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Resources



Title: Multiple sclerosis for dummies
 Author: Rosalind Kalb
 Published: 2012
 Availability: Print and eBook
 Accessible, easy-to-understand information about what happens with multiple sclerosis – what kinds of symptoms it can cause, how it can affect your life at home and at work, what you can do to feel and function better, and how you can protect yourself and your family against the long-term unpredictability of the disease.



Title: Navigating life with multiple sclerosis
 Authors: Kathleen Costello, Barbara Giesser and Ben Thrower
 Published: 2015
 Availability: eBook
 Multiple sclerosis may cause a myriad of symptoms and varies greatly from person to person. The authors demystify the illness and offer practical solutions and guidance based upon their extensive combined clinical and research experience.

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The National Disability Insurance Scheme



A major change to the way disability supports and services are funded and delivered

- Available to people who are: under 65, satisfy residency requirements and are able to demonstrate that their disability substantially affects daily living
- Promoting choice, control and social and economic participation
- Providing a whole-of-life approach
- It is not means tested
- Providing reasonable and necessary supports and services
- Ensuring equity of access

We can help you to



- understand the eligibility requirements
- understand the pathways to access the NDIS
- prepare for a planning conversation
- understand your current supports and any unmet need
- develop your goals

Please call MS Connect on 1800 042 138 to have an NDIS conversation

We are a 'Registered Provider'



Once you have an NDIS approved plan MS is registered with National Disability Insurance Agency to deliver:

- Support Coordination – assistance to help make your plan active
- Residential Respite
- Social Support Day Program (Vic)
- Exercise physiology and personal training (NSW)
- Specialist Continence Assessment (NSW)
- Physiotherapy and Occupational Therapy (NSW and Vic)

Want to learn more - please call MS Connect