



Welcome to today's webinar:

Brain Health

Your Presenter is Jodi Haartsen
Your Facilitator is Andrea Salmon

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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.

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Introduction to Presenter






Jodi Haartsen is Executive Manager of Client Engagement & Wellbeing at MSL. She started MS health care over 20 years ago as part of a nursing career in general neurology, neurosurgery, nursing education and research.

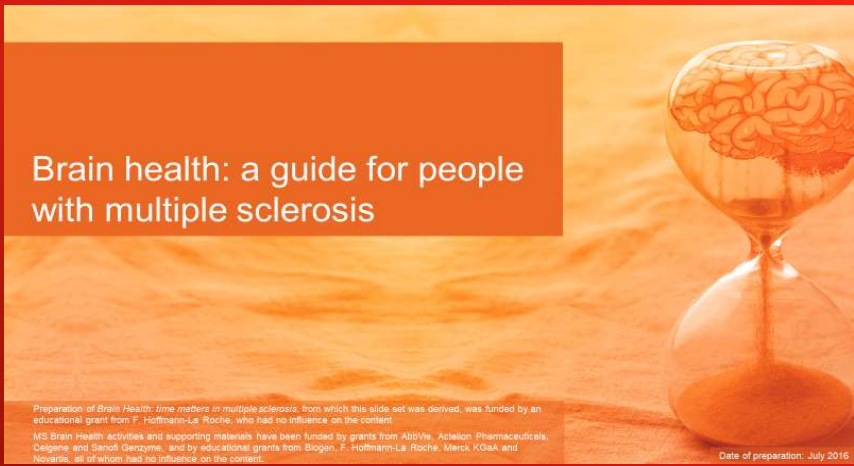
Jodi's roles have included MS Nurse Practitioner and Manager of the MS clinic at Eastern Health, MS researcher and MS educator.

She is a member of the global MS Brain Health Steering Committee and is passionate about the MS Brain Health initiative. She has studied Master of Nursing and Naturopathy.

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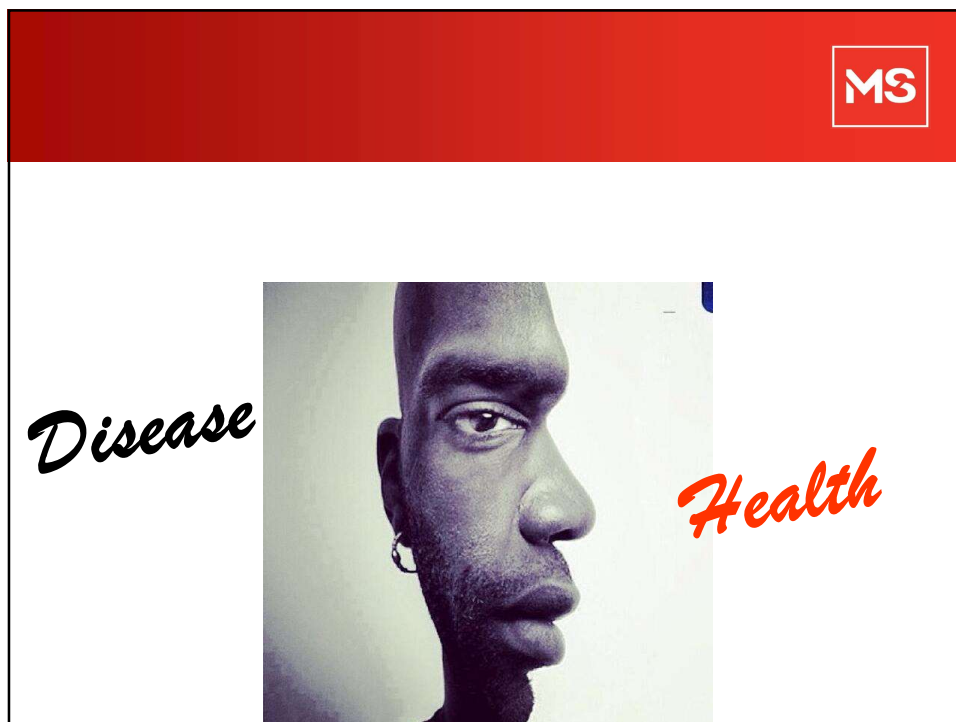
Brain health: a guide for people with multiple sclerosis

Preparation of Brain Health: time matters in multiple sclerosis, from which this slide set was derived, was funded by an educational grant from F. Hoffmann-La Roche, who had no influence on the content.

MS Brain Health activities and supporting materials have been funded by grants from AbbVie, Actelion Pharmaceuticals, Celgene and Sanofi Genzyme, and by educational grants from Bogen, F. Hoffmann-La Roche, Merck KGaA and Novartis, all of whom had no influence on the content.

Date of preparation: July 2016.

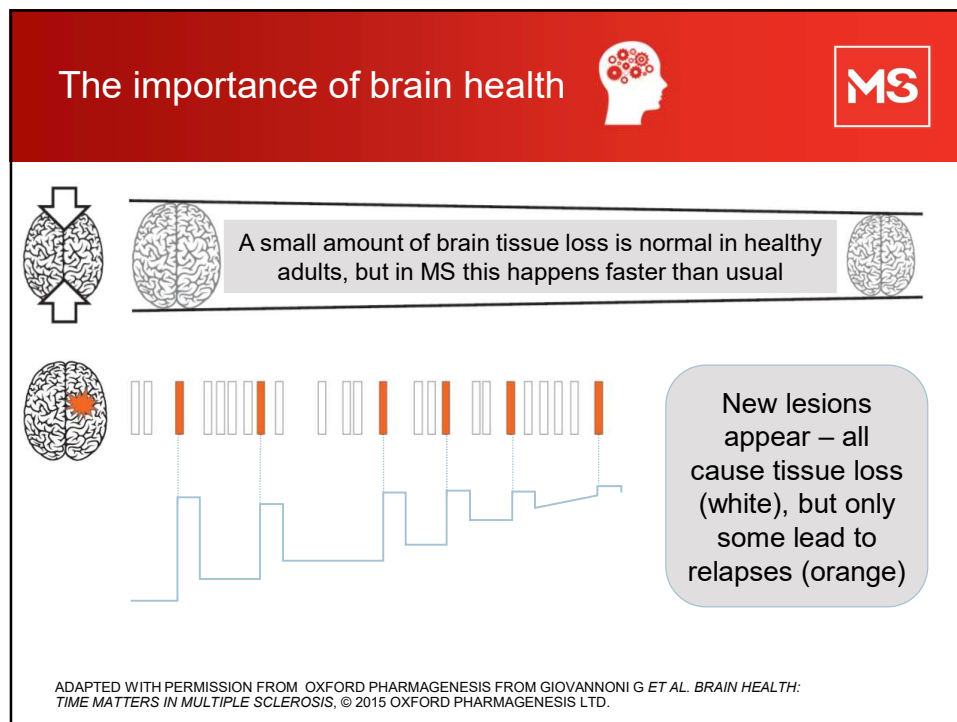
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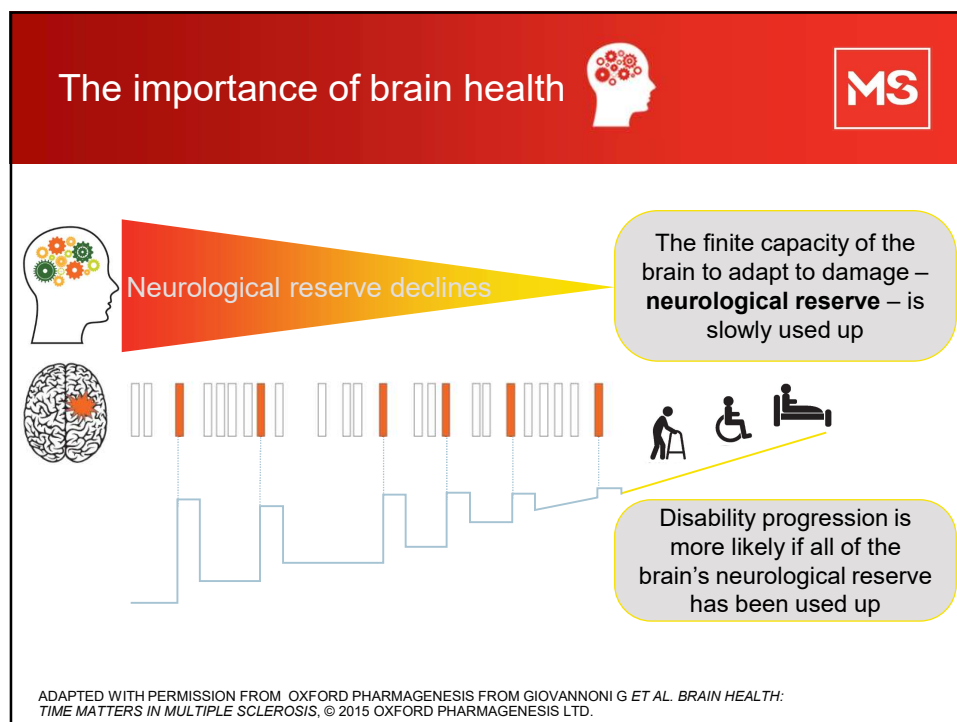
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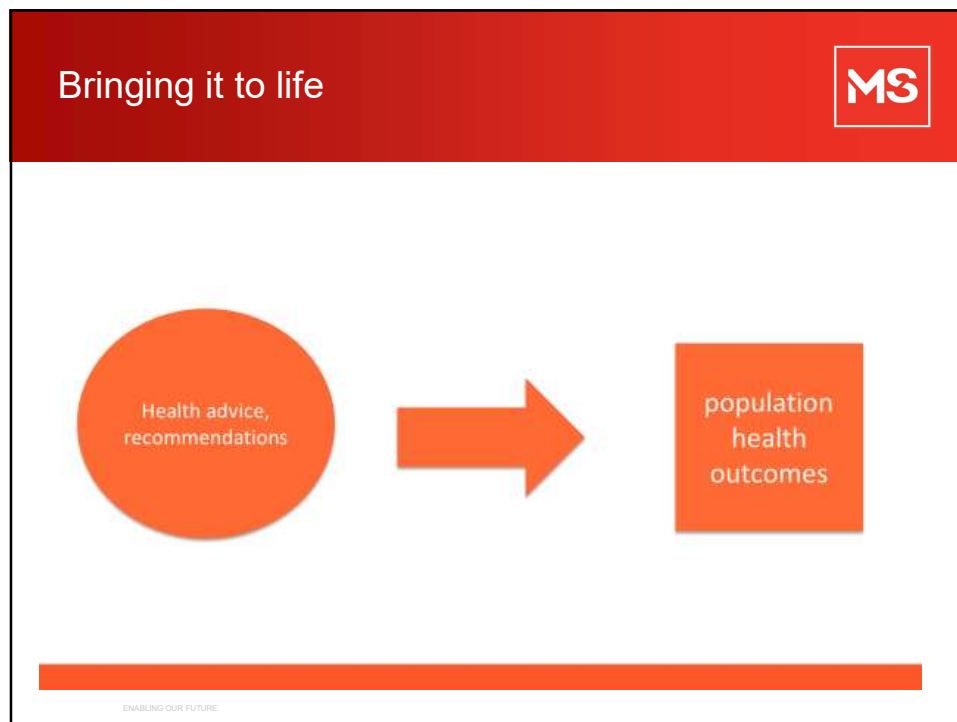
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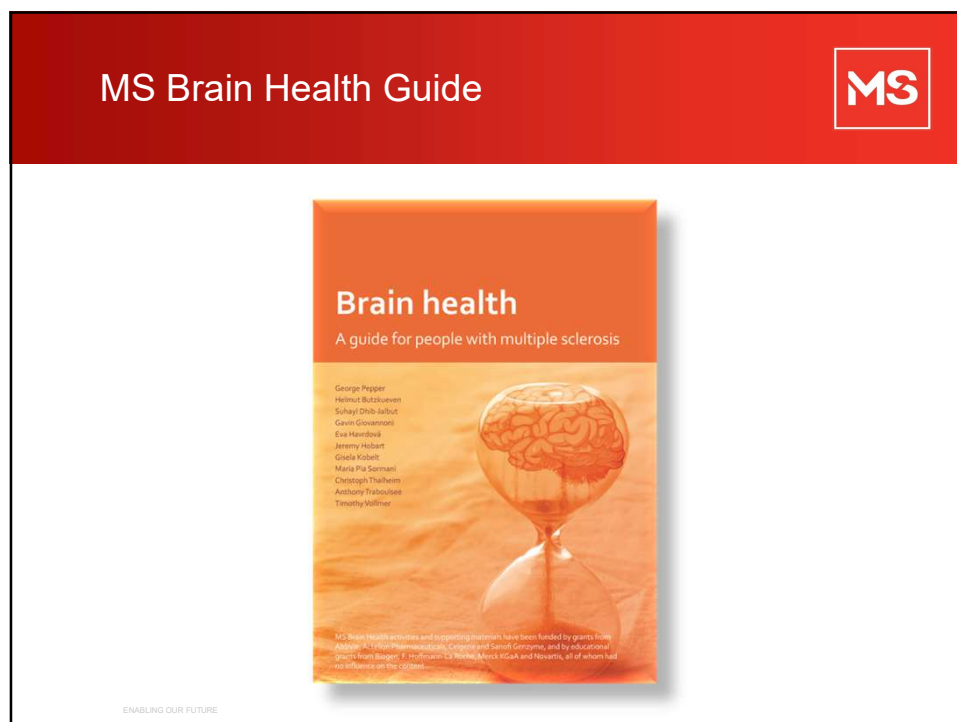
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Recommendations of the guide for people with MS


The guide recommends keeping your brain as healthy as possible


It recommends:




Understanding the importance of brain health




Living a brain-healthy lifestyle




Earliest possible referral and diagnosis



Monitoring of disease activity



Early treatment with an appropriate DMT




Informed, shared decision-making

DMT, DISEASE-MODIFYING THERAPY

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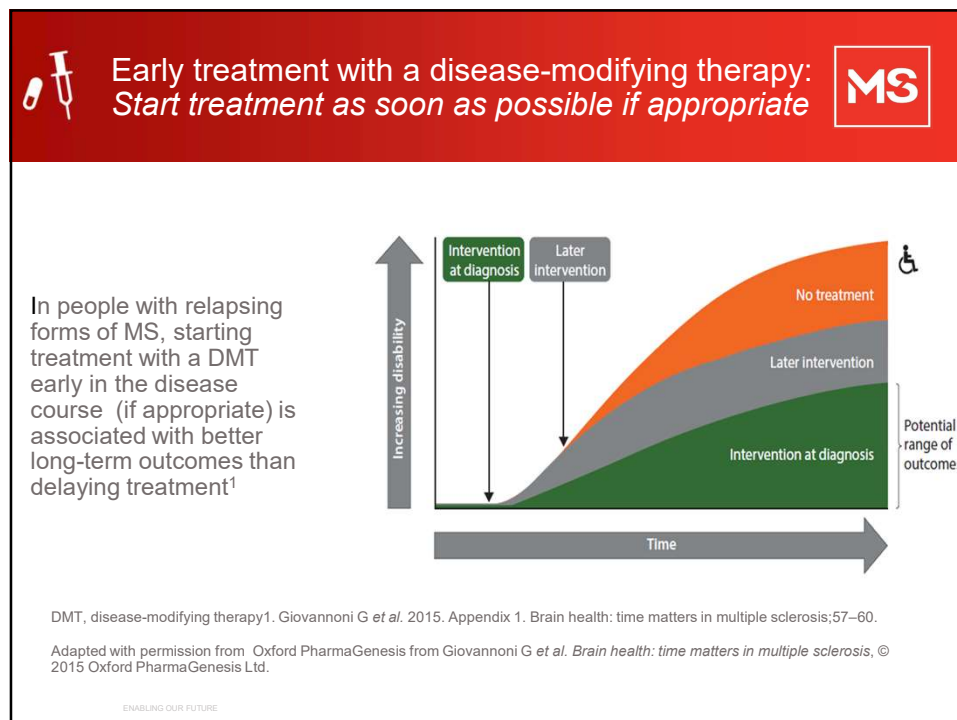
Early referral and diagnosis


- ✓ Ask for urgent referral to a neurologist if MS is suspected, preferably to one with a special interest in MS, or to an MS specialist clinic
- ✓ Request early access to diagnostic procedures, including MRI

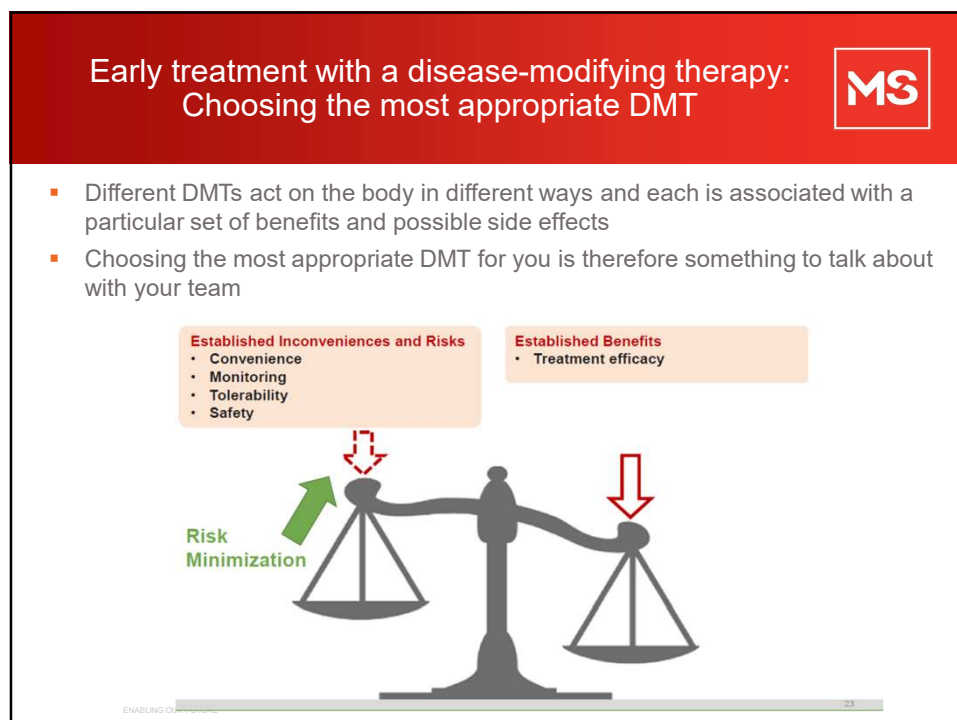
It is now possible to diagnose MS earlier than ever before, thanks to evidence from MRI brain scans¹
- ✓ Stay in touch with your MS team for ongoing monitoring if you do not receive a diagnosis straight away

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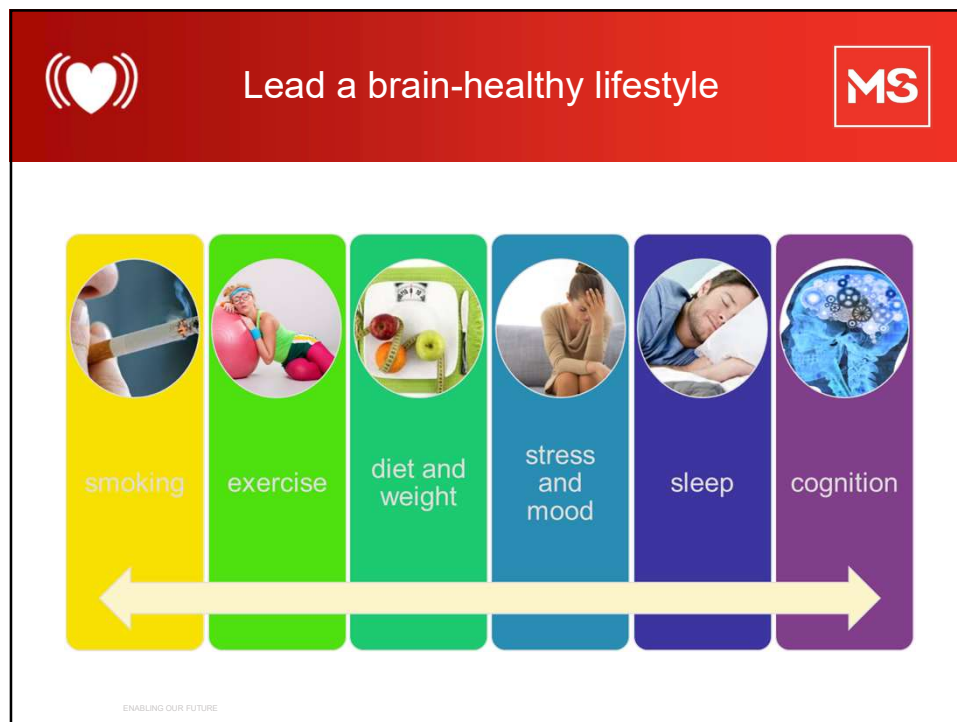
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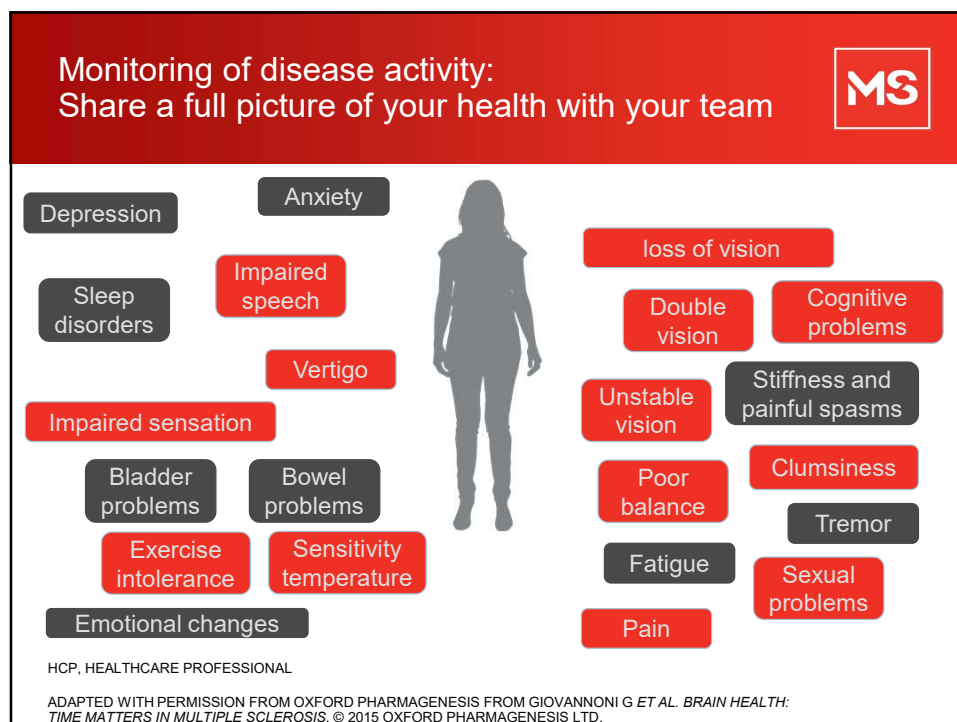
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Monitoring of disease activity:

Share a full picture of your health with your Health care team







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Monitoring of disease activity:

Monitoring is key to maximizing lifelong brain health



Regularly monitoring disease activity using MRI can give early warning that MS is not responding well to treatment

This is because there is more to MS disease activity than meets the eye

Disease activity in the form of lesions and brain tissue loss can predict relapses and disability progression¹

All disease activity damages tissue in the brain and spinal cord even if this doesn't immediately lead to a relapse

Disability progression

Relapses

Lesions detectable using standard clinical MRI techniques (white matter)

Brain tissue loss

MRI or clinical evidence that disease activity is poorly controlled should prompt discussion about the possibility of switching to a DMT that acts on the body in a different way

1. GIOVANNONI G ET AL. 2015. APPENDIX 2. BRAIN HEALTH: TIME MATTERS IN MULTIPLE SCLEROSIS; PP61-63

ADAPTED WITH PERMISSION FROM OXFORD PHARMAGENESIS FROM GIOVANNONI G ET AL. BRAIN HEALTH: TIME MATTERS IN MULTIPLE SCLEROSIS, © 2015 OXFORD PHARMAGENESIS LTD

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Monitoring of disease activity:
Monitoring is key to maximizing lifelong brain health

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Informed, shared decision-making

MS

- Decisions about DMTs should be informed and shared between you as a person with MS, and your health care team
- You should feel able to discuss your values, needs, limitations, lifestyle, treatment goals and the likely disease course with your health care team

When people with MS have open, trust-based relationships with all their teams, they are more likely to continue with treatment,¹ and so are less likely to experience serious relapses²

DMT, disease-modifying therapy; HCP, healthcare professional

1. de Seze J et al. *Patient Prefer Adherence* 2012;6:263–73; 2. Bunz TJ et al. *Value Health* 2013;16:A109

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What can you do?





Understanding the importance of preserving brain health

- ✓ Be aware that MS disease activity may be ongoing even when you feel well and that this can threaten brain health
- ✓ Discuss neurological reserve and brain health with others, including health care team





Early referral and diagnosis

- ✓ Ask for urgent referral to a neurologist if MS is suspected, preferably to one with a specialist interest in MS, or to an MS specialist clinic
- ✓ Request timely access to diagnostic procedures, including MRI
- ✓ Stay in touch with your MS team if you do not receive a diagnosis straight away

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What can you do?





Early treatment with a disease-modifying therapy (when appropriate)

- ✓ Ask your health care team whether it is appropriate to start treatment with a DMT
- ✓ Find out what options are available



Living a brain-healthy lifestyle, including treating other diseases

- ✓ Embrace a brain-healthy lifestyle that includes keeping physically active, keeping your weight under control, keeping your mind active, not smoking, watching how much you drink and taking any prescribed medications

DMT, DISEASE-MODIFYING THERAPY

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What can you do?



A plan to monitor MS disease activity and to switch therapy if treatment is not working

- ✓ Keep an MS diary and share this information with your HCPs
- ✓ Discuss strategies for managing your MS
- ✓ Ask the health care team who oversee your treatment how they plan to monitor your MS
- ✓ Ensure that you feel well informed about the results of your clinical assessments and MRI scans
- ✓ Ask whether it is appropriate to switch to another DMT



Informed, shared decision-making

- ✓ Be part of the decision-making process together with your HCPs
- ✓ Prepare for your appointments by making notes about topics you would like to discuss
- ✓ Explain to your HCPs what matters to you
- ✓ Look for other resources to help with these conversations
- ✓ Your local MS patient organizations may be able to help

DMT, DISEASE-MODIFYING THERAPY; MRI, MAGNETIC RESONANCE IMAGING

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Report endorsed by professional societies and advocacy groups





UPDATED 22 AUGUST 2018. ENDORSEMENTS RECEIVED SINCE THIS DATE CAN BE FOUND AT WWW.MSBRAINHEALTH.ORG.

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MS Brain Health
Time Matters

Our vision is to create a better future for
people with MS and their families

Your voice will help to effect this change

Commit to supporting the MS Brain Health recommendations at www.msbrainhealth.org

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Questions




MS Connect
1800 042 138
msconnect@ms.org.au

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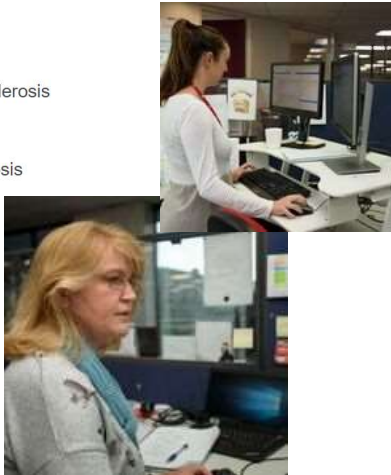
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MS Connect



10 reasons to call us:

1. Up-to-date, evidence based information about multiple sclerosis
2. Expert advice on managing symptoms
3. Information about minimising the impact of multiple sclerosis
4. Support for people who are newly diagnosed
5. Information about treatment options
6. Education programs
7. Connections to other people living with multiple sclerosis
8. Referrals to appropriate services in your area
9. Extra support for you and your family
10. Respite options to give families short-term breaks



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Peer Support




- ❖ 1:1 Phone Support
- ❖ Face to Face groups -
(temporarily converted to Telegroups)
 - 2 in the ACT
 - 11 in Tasmania
 - 17 in NSW
 - 42 in Vic
- ❖ Telegroups
 - Currently running 12 telegroups
- ❖ Facebook groups
 - 3 groups – for people living with MS
 - for carers
 - for young carers – up to 25 years of age



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Get Your Act Together



- Online Tool – designed to help you better manage your multiple sclerosis symptoms
- Focuses on some of the common symptoms of MS – emotions, fatigue, continence, cognition, pain and heat sensitivity
- Designed for people living in the ACT but includes useful information for all people living with MS
- Complete the tool to receive a personalized report (listing services, resources, tips etc)

Visit www.ms.org.au and search Get Your Act Together

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Employment Support Services



The MS Employment Support Service (ESS) is the only MS specialist employment service for people living with multiple sclerosis in Australia that can help you succeed at work, whether that is staying in your current job or finding new employment.


Contact MS Connect for more information on free call 1800 042 138.



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Registered NDIS Provider



MS is a registered NDIS provider in NSW, ACT, Vic and Tas and is approved to provide:
(Pls note: Face to face services/programs have been either converted to online programs or postponed)

- Assistance with 'Access Request Forms', Access rejections and pre-planning
- Support Coordination – assistance to help make your plan active
- Plan Management
- Short term accommodation (Vic)
- Group activities – yoga, dance for health, exercise (NSW)
- Exercise Physiology (NSW)
- Specialist Continence Assessment (Vic)
- Occupational Therapy (NSW and Vic)
- Physiotherapy (NSW)

Want to learn more?
Please call
MS Connect
1800 042 138

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My Aged Care



My Aged Care is an Australian Government initiative, website and phone line to help you find about aged care services.

Available to people who are 65 years of age and over.

Why Contact My Aged Care?

- ✓ Information
- ✓ Assistance in mapping out your needs
- ✓ An assessment for further supports

Phone: 1800 200 422 Free call Australia wide

Website: <https://www.myagedcare.gov.au>

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Podcasts for Clients






PODCASTS

<https://www.ms.org.au/support-services/education/podcasts.aspx>

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Thank you



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Please stay on after this webinar to complete a short survey.

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