

Leveraging digital technologies to increase health promoting behaviours in a regional population of people with multiple sclerosis.

Evaluation on pilot program in Orange, Central West NSW

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Disclosures

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- I received a travel grant to attend the MSNA conference from Merck.

The regional context

Regional and rural Australians experience poorer health

- Limited infrastructure
- Less access to goods and services
- Less employment and educational opportunities
- Higher prevalence of health risk factors
- Shortages of health professionals
- Maldistribution of health workforce

When compared to metropolitan counterparts, rural and remote Australians:

- Generally have lower incomes but pay higher prices for goods and services.
- Less likely to have employment
- Less likely to have completed Year 12 or a non-school qualification
- Less educated. 8% of regional Australians have a Bachelor's degree or tertiary equivalent, compared to NSW average 16.2%
- 70% are overweight or obese
- Higher prevalence of diseases such as coronary heart disease, type 2 diabetes, chronic kidney disease, lung conditions correlates with remoteness

Health promoting behaviours

Increasing capacity for self management through education

- Physical activity
- Diet
- Mental health management
- Medication usage
- Fatigue management
- Allied health engagement
- Employment support

My role as MS Nurse

- Private practice in Orange NSW, with two regular consultant neurologists Professor Simon Hawke and Dr Emma Blackwood
- 1 MS nurse to growing base ~318 patients
- My role is part-time, 3 days a week
- Patient contact primarily over the phone, or via emails
- Occasionally face-to-face meetings, more frequent for Orange locals

Central West Region, NSW



What does living in a regional or rural location look like for the person with multiple sclerosis?

- Limited access to specialists and MS nurse
 - Need to travel significant distances for specialist care; limited public transport
 - Need to travel for infusion DMTs
 - Need to travel to pharmacy in other towns
 - Limited GP appointments,
 - Need to travel for allied health
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- Limited access to primary care generally means less use of services

Our pilot education program

Objective: To increase health promoting behaviours in a regional population of people with multiple sclerosis using digital technologies such as email newsletters and webinars

- **Monthly newsletter sent via email**
 - Maximum of three topics
 - Links to reputable information and sources
- **Three live webinars with Professor Hawke and myself**
 - Research updates
 - Requested topics discussed.

Monthly newsletter



CENTRAL WEST NEUROLOGY &
NEUROSURGERY



March Newsletter

Welcome to our first newsletter for 2022. We hope to provide a short round-up of practical info that you can access from wherever you are.

Survey

Thank you to everyone who has completed our survey! If you haven't already there is still time.

Completing this survey will help us understand more of your experience as a MS patient in regional NSW, so that we can improve how we care for you.

The NDIS

What is the NDIS?

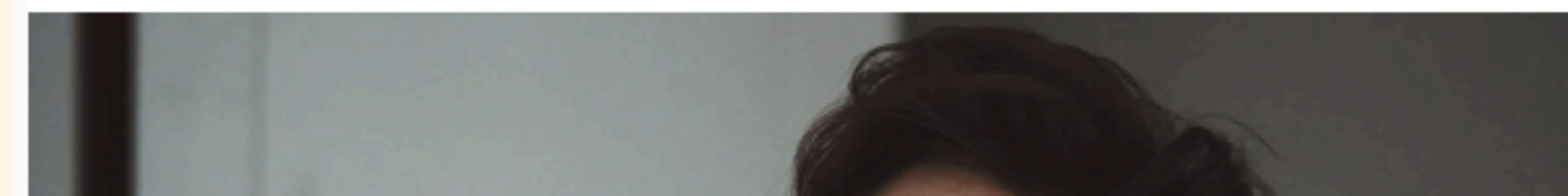
The NDIS is the National Disability Insurance Scheme, and is designed to provide support for eligible people. To be eligible you must be under 65, an Australian citizen or have a Permanent visa, and MS stops you from doing everyday tasks yourself.

How do I access it?

Many MS patients have accessed the NDIS, so to have a chat about whether you meet the criteria to become an NDIS participant, give **MS Connect** a call on **1800 042 138**.

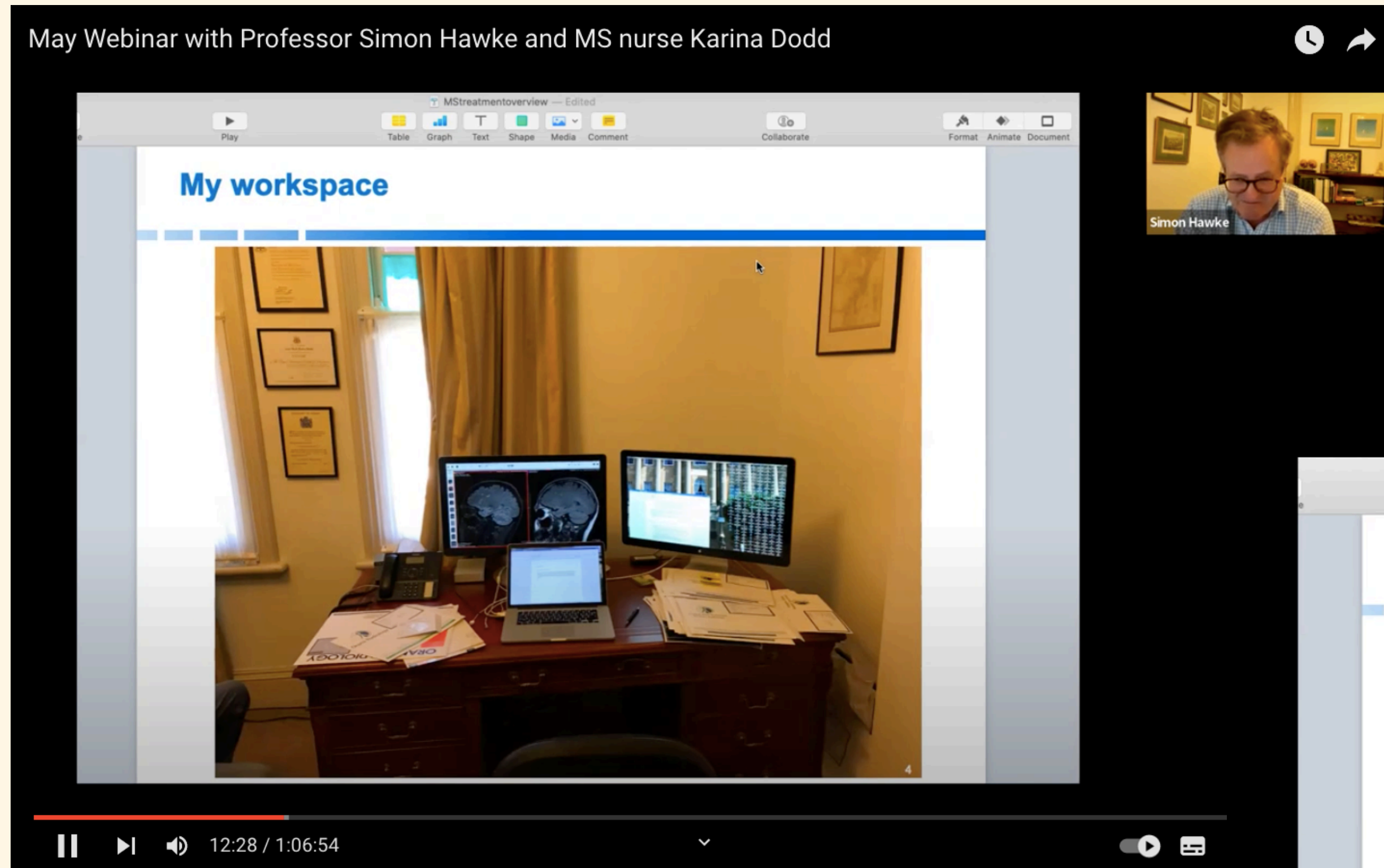
They can then provide the next steps in planning your application, and creating a document which you can then send to us to assist in completing the 'Treating Professional' section.

[Find out more about MS and the NDIS](#)



Three live webinars on Zoom

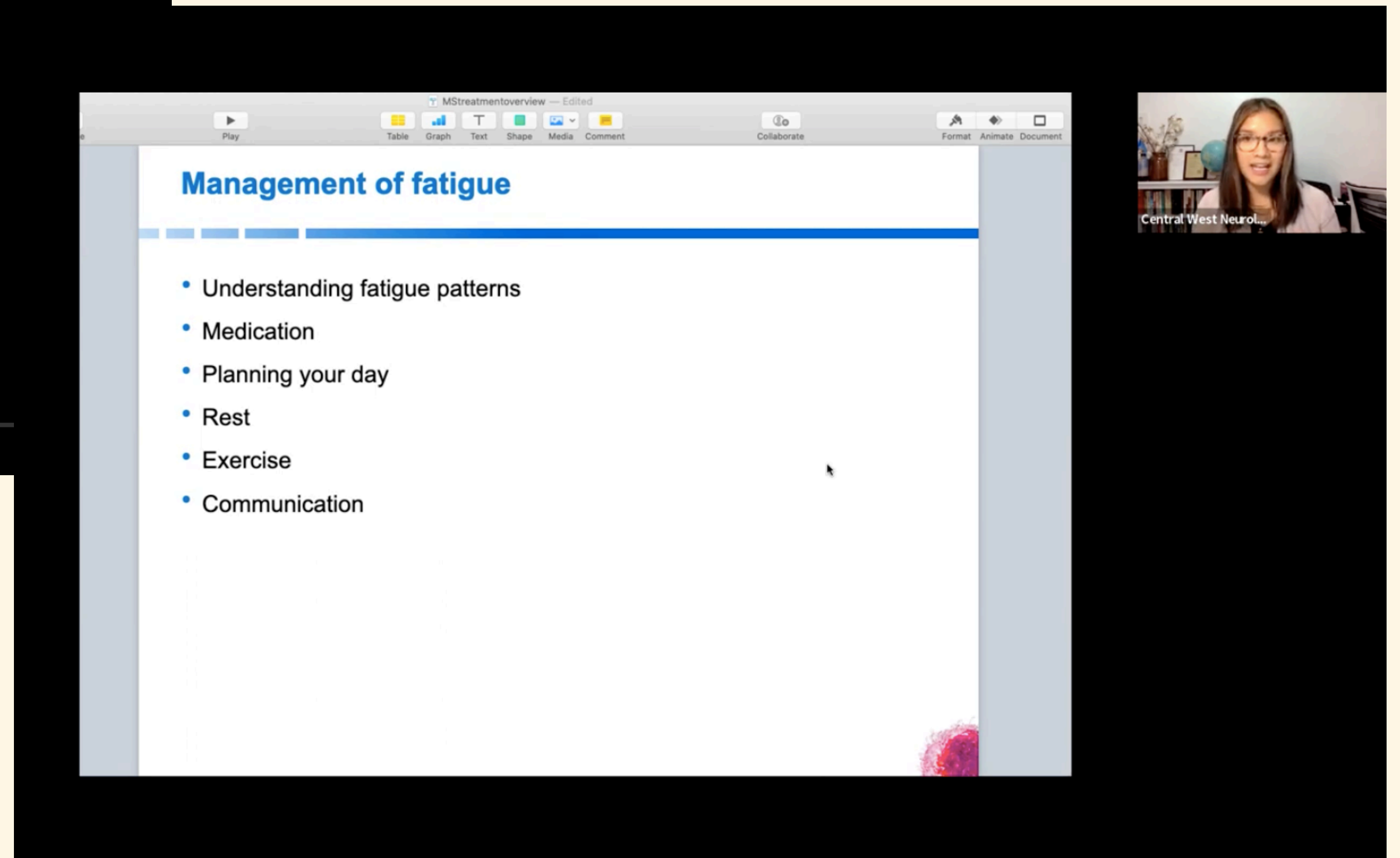
May Webinar with Professor Simon Hawke and MS nurse Karina Dodd



My workspace

Simon Hawke

12:28 / 1:06:54



Management of fatigue

- Understanding fatigue patterns
- Medication
- Planning your day
- Rest
- Exercise
- Communication

Central West Neurol...

Person-centred design

Topics requested

- Update on research
- Fatigue management
- Diet
- Exercise
- Covid-19
- New MS treatments
- Bowel/bladder management
- Support for living with MS

Post test survey findings (n=46)

- Likert scale survey questions evaluation
- Email and physical letter mailout
- Feedback that people weren't aware of any program

Here's what we learnt.

Newsletters vs Webinars

- People engaged with newsletters more than the webinars (93% vs 71.7%)
- People found the information **easy to understand** at an equal level from both resources
- Information on the newsletters was more effective than webinars at **increasing understanding of MS**
- People agreed that newsletters helped them manage their symptoms more than webinars
- Overall, newsletters were more effective at helping people with MS

Assumptions

- Whilst feedback from the webinars was still positive, further investigating will be required to find out what improvements can be made
- Factors to consider include: time of day, easy access to replays, length of webinar
- Newsletters were short and succinct. They were monthly, did this serve our patient population better?
- Digital literacy: people of all demographics are more familiar with using emails, not all are as familiar with using webinars

Key findings

Newsletters

- 1. **Easy to understand 86.9%** Education is most successful when it's understood
- 2. **Added to understanding of MS 80.5%** Giving people the required knowledge and confidence to live with their condition
- 3. **Helped manage their symptoms 80.5%** Empowering people on how to self manage the symptoms can reduce their pain and improve their quality of life

Health promoting behaviours

Made changes in their diet - 41.3%

- Webinar: Discussed gut microbiome, and gave an overview of main diet approaches such as ketogenic, Wahls protocol, Swank diet, Overcoming MS diet, intermittent fasting, key takeaways
- Newsletter link to **MS Modifiable Lifestyle Guide**
- As a result of information presented in newsletters and webinars, 41.3% of respondents made changes in the their diet

Health promoting behaviours

Made changes in the way they exercise - 50%

- Discussing heat sensitivity (drinking cold water, pre-cooling, using cooling vests, air conditioning)
- Video links to sitting exercises, newsletter links to resources such as **MS Modifiable Lifestyle Guide**
- Encouraging physical activity for everyone
- Physical activity has benefits for physical function, fatigue, mental health
- As a result of the information presented in the newsletters and webinars, 50% of respondents agreed that they made changes in the way that they exercised

Benefits of using digital technology

Increasing access through existing infrastructure

- Low cost: for both practitioners and patients
 - High reach: increasing our impact
 - Time effective
 - Awareness of existing support increased
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- Low levels of digital literacy can be a barrier.

Future work

- Currently expanding the program to other regional centres in NSW, Victoria and Qld
- More opportunities to collaborate with other regional and rural health professionals
- Program to include a central website where we can host recordings for people to access videos and regional and rural people with MS can find things for their specific needs

Acknowledgements

- All the staff at Central West Neurology & Neurosurgery
- The wonderful patients of CWNN that support our clinical and basic scientific research
- Previous work has been supported by: Dubbo MS Support Group

The Merck logo, featuring the word "MERCK" in a bold, blue, sans-serif font.

NOVARTIS

The Sanofi logo, featuring the word "SANOFI" in a blue, sans-serif font, followed by a stylized logo consisting of a green leaf and a blue wave.The Roche logo, which features the word "Roche" in a blue, sans-serif font, enclosed within a blue hexagonal border.

RESEARCH
AUSTRALIA

Caption

Recent studies our patients have supported

Professor Simon Hawke

[IgG3 + B cells are associated with the development of multiple sclerosis.](#) Marsh-Wakefield F, Ashhurst T, Trend S, McGuire HM, Juillard P, Zinger A, Jones AP, Kermode AG, Hawke S, Grau GE, Hart PH, Byrne SN. Clin Transl Immunology. 2020 Apr 29;9(5):e01133. doi: 10.1002/cti2.1133. eCollection 2020 May. PMID: 32355561

[Selective modulation of trans-endothelial migration of lymphocyte subsets in multiple sclerosis patients under fingolimod treatment.](#) Hawke S, Zinger A, Juillard PG, Holdaway K, Byrne SN, Grau GE. J Neuroimmunol. 2020 Dec 15;349:577392. doi: 10.1016/j.jneuroim.2020.577392. Epub 2020 Sep 24.

[Cladribine Reduces Trans-Endothelial Migration of Memory T Cells across an In Vitro Blood-Brain Barrier.](#) Ford RK, Juillard P, Hawke S, Grau GE, Marsh-Wakefield F. J Clin Med. 2022 Oct 12;11(20):6006. doi: 10.3390/jcm11206006.

[Peripheral B-cell dysregulation is associated with relapse after long-term quiescence in patients with multiple sclerosis.](#) Marsh-Wakefield F, Juillard P, Ashhurst TM, Juillard A, Shinko D, Putri GH, Read MN, McGuire HM, Byrne SN, Hawke S, Grau GE.

[Circulating Memory B Cells in Early Multiple Sclerosis Exhibit Increased IgA+ Cells, Globally Decreased BAFF-R Expression and an EBV-Related IgM+ Cell Signature.](#) Leffler J, Trend S, Ward NC, Grau GE, Hawke S, Byrne SN, Kermode AG, French MA, Hart PH. Front Immunol. 2022 Feb 16;13:812317. doi: 10.3389/fimmu.2022.812317. eCollection 2022.

Trans-Endothelial Migration of Memory T Cells Is Impaired in Alemtuzumab-Treated Multiple Sclerosis Patients. Nguyen K, Juillard P, Hawke S, Grau GE, Marsh-Wakefield F. Journal of Clinical Medicine. 2022; 11(21):6266. <https://doi.org/10.3390/jcm11216266>

Circulating CCR6+ ILC proportions are lower in multiple sclerosis patients. Florentina Aglas-Leitner, Pierre Juillard, Anette Juillard, Scott N Byrne, Simon Hawke, Georges E Grau, Felix Marsh-Wakefield. Clin Transl Immunology. 2022:e1426. doi: 10.1002/cti2.1426