

FINDING HOPE WITH OMS

Webinar series

Living Well with Progressive MS

Wednesday, July 21st at 11am BST

Hosted by



Helen Rees Leahy



Phil Startin



OVERCOMING
MULTIPLE
SCLEROSIS

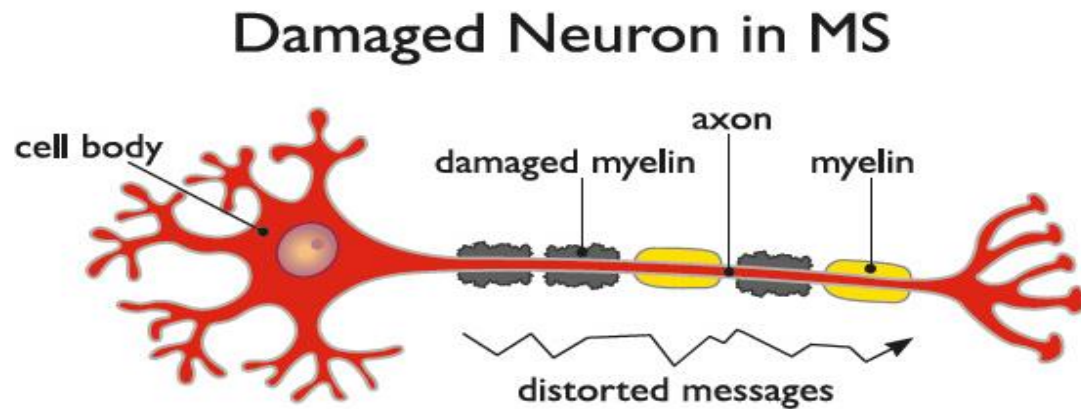
Welcome

Agenda – Living well with PMS

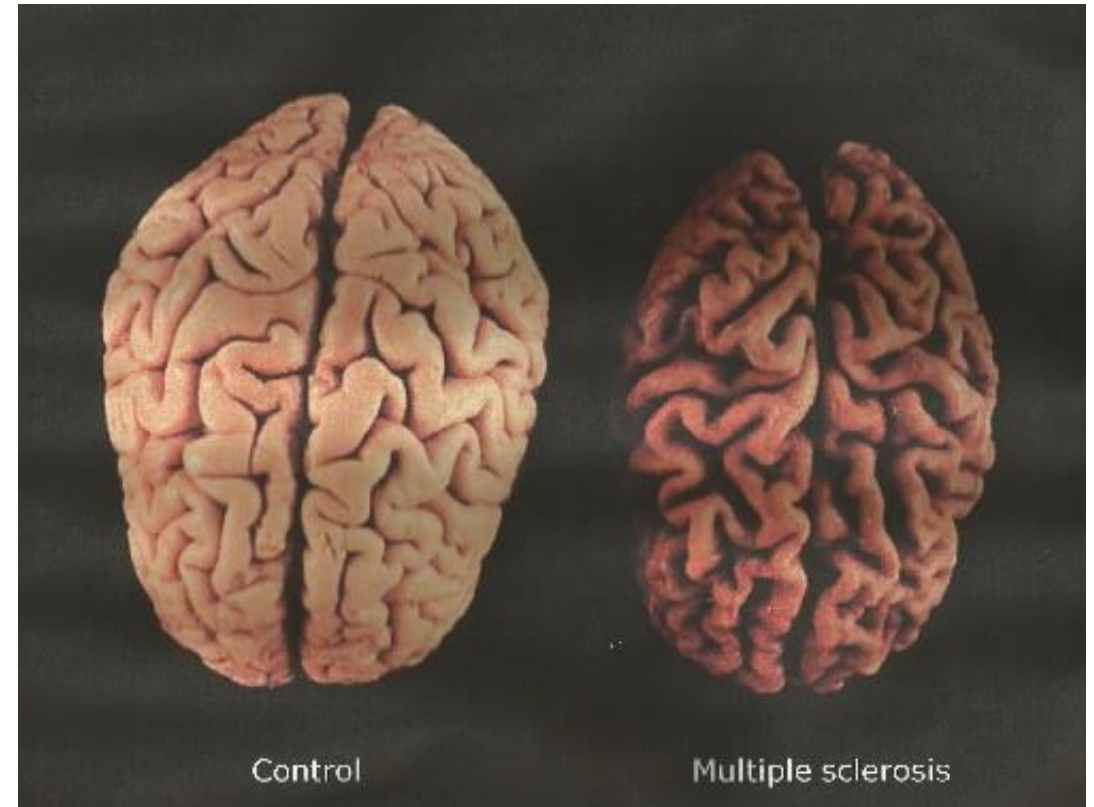
- Welcome and introductions
- What is Progressive MS?
- Challenges of living (well) with Progressive MS
- Does the Overcoming MS program work for people with PMS?
- Our experiences of “overcoming MS”
- Q&A

What actually happens in PMS is different from RRMS

RRMS



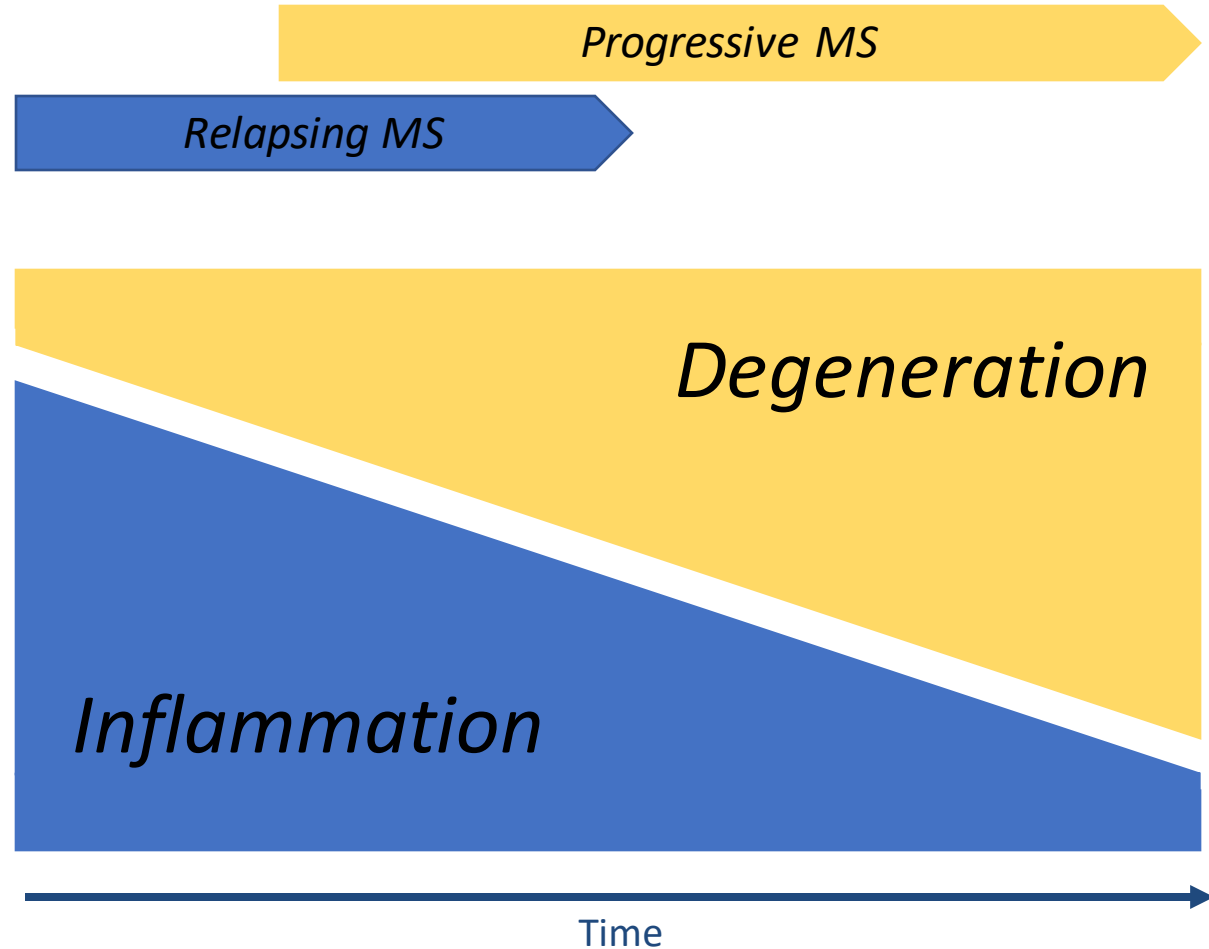
PMS



Dr Ben Turner

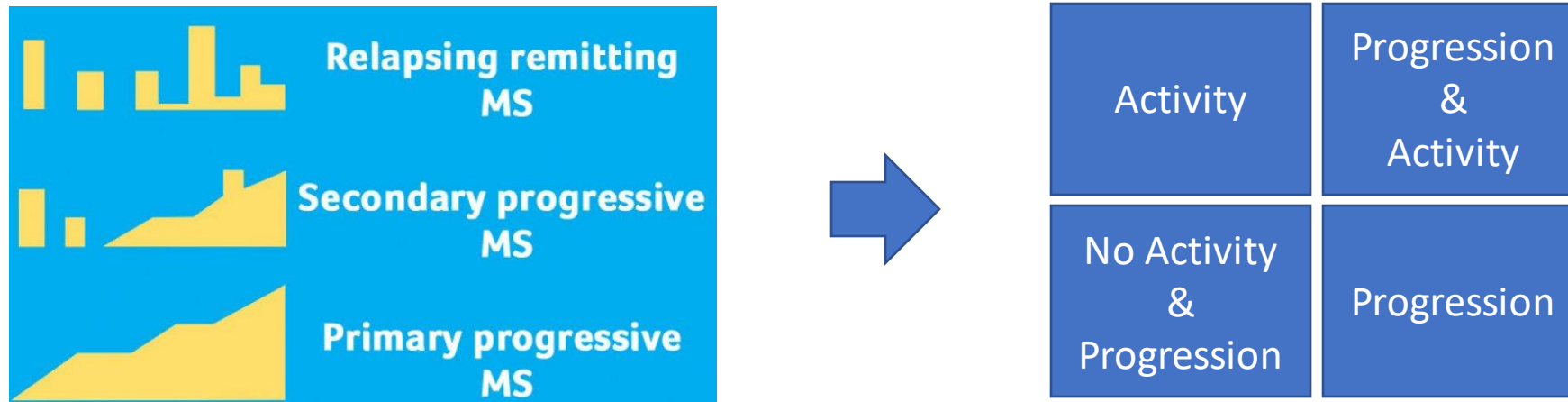
Indeed, what is MS?

MS is a “spectrum” with an inflammatory component and a neurodegenerative component (Curr Opin Neurol. 2015, D Ontaneda and R J Fox) and **both** can be present



The “labels” are changing....

MS healthcare professionals (neurologists, MS nurses) refer less to the traditional MS subtypes defined in 1996, and increasingly define the condition in terms of “activity” and “progression”



Challenges of living (well) with Progressive MS

- Negative perceptions of Progressive MS ('bad' vs 'good' MS)
- Being a minority in the MS population (implications for research and treatment)
- Being a minority in the OMS community
- Living with uncertainty about the future

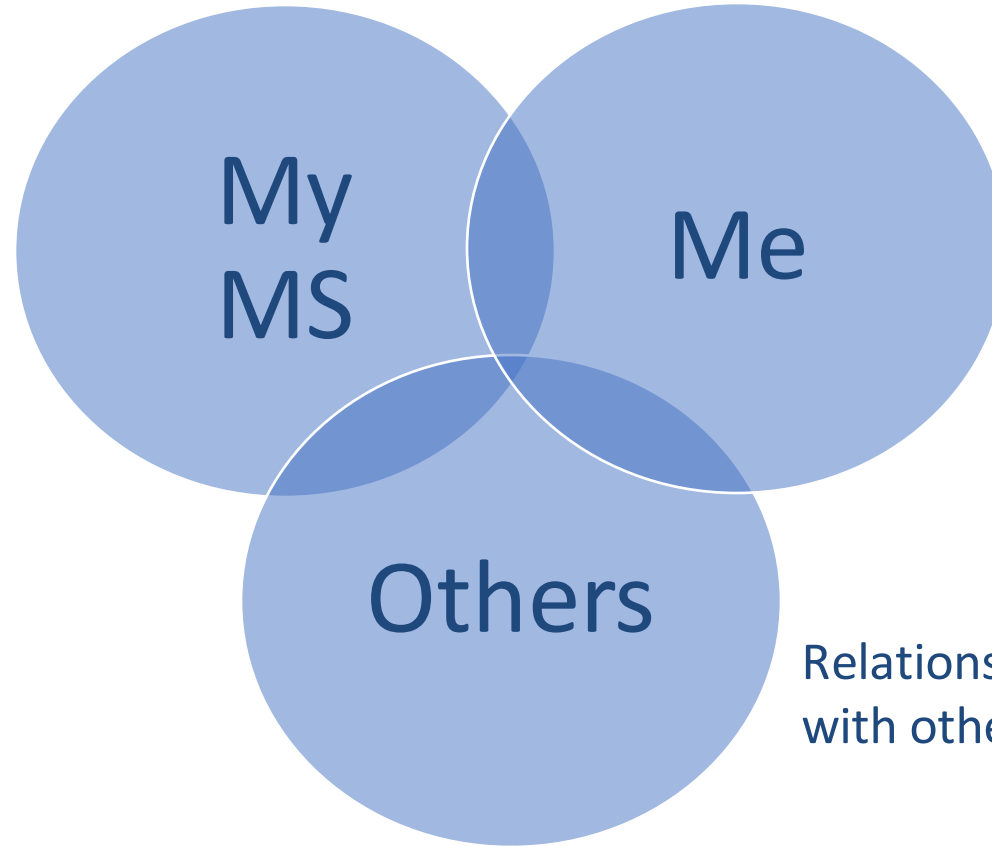
All forms of MS are “unpredictable” but there are some specific challenges for progressive MS

Relapses and progression

Physical/cognitive symptoms and capability

Pain and ‘hidden’ symptoms

Denial ... acceptance continuum



My identity – who I am

What’s important to me

How I want to live my life – livelihood and leisure

Relationships with others

Self Activation

- ‘The knowledge, skills and confidence a person has in managing their own health and health care.’
- The relationship between self activation and health outcomes
- Becoming/finding your own health advocate
- Empowerment and OMS

Does the Overcoming MS program work for people with PMS?



Exercise and PMS – biggest return?

Extensive evidence that exercising can help us:

- recover/stop physical symptom loss
- improve quality of life and motivation
- develop new neural pathways
- increase neuroprotective and regenerative capacity
- improve the function and maintenance of synapses

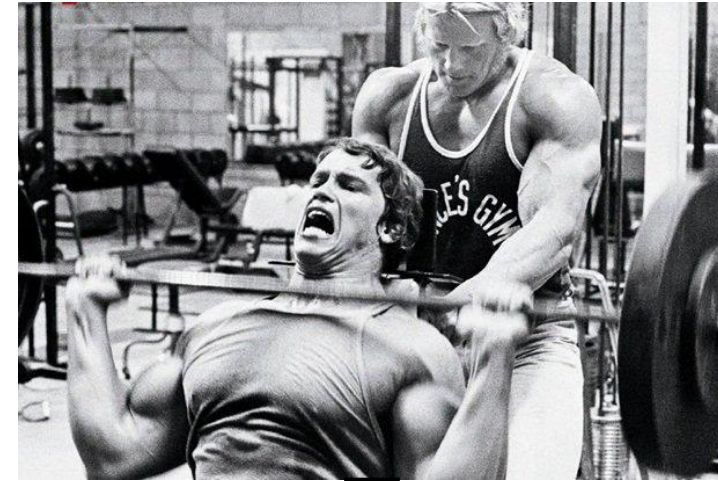


“exercise should be classified as a disease-modifying treatment for MS and that everyone with MS should be enrolled in an exercise programme of some description”

Professor Gavin
Giovannoni
Chair of Neurology, Barts

Less of the “what”, more of the “how”

- Find something that you enjoy, that you will keep doing, that enthuses you
- Form is important as you’re literally rewiring your brain
- Be safe, be kind, try not to judge
- Goals can be helpful, but perhaps hold them more lightly



Start where you are.
Use what you have.
Do what you can.
-Arthur Ashe

Stress and PMS – it matters!



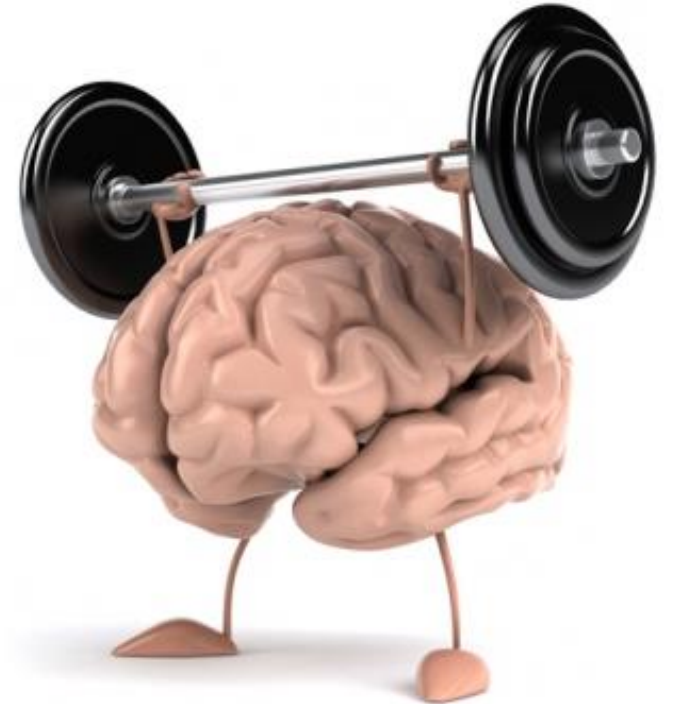
For me living with PMS is a “mind game” and meditation helps!

Typically we “live” in our heads

- dealing with physical symptoms and consequences
- living with new “norms”, judging and evaluating

Mindfulness really is “training” for the day to day....

- improving attention & awareness
- ability to reframe and respond skilfully rather than reacting
- understanding you, your identity, your values
- acceptance & kindness



Self Compassion

- What's important to me? Reviewing your values and goals
- Recalibrating your achievements
- Building your support team
- Recognising and rejecting 'toxic positivity'
- Finding pleasure and meaning in daily life, including self-care
- Pacing yourself

Our experiences of “overcoming MS”



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Q & A

[For more information on the Finding Hope with OMS webinar series visit
https://overcomingms.org/community/events](https://overcomingms.org/community/events)