



Dealing with a Diagnosis of Multiple Sclerosis: Differences in Post-Diagnosis Behaviour

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Multiple Sclerosis



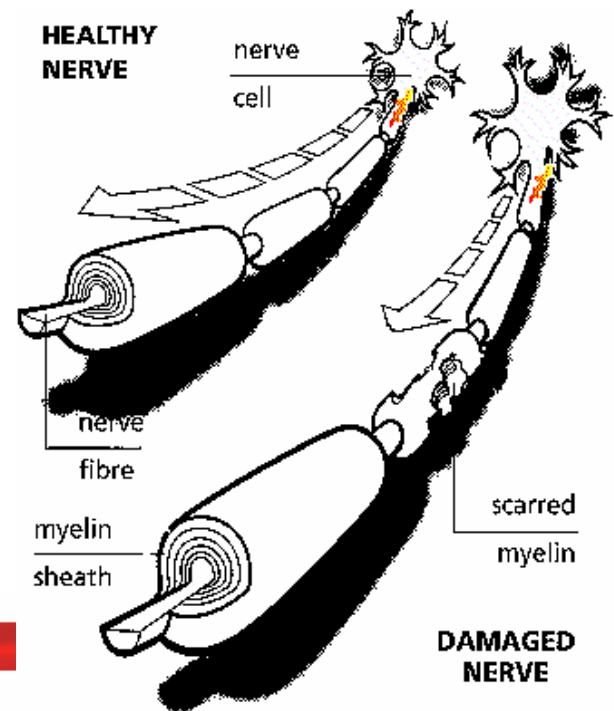
- The most common neurological disease of young Australians
- Australian prevalence ~ 15,000
- MS Society of Victoria
> 4000 registrations

Who gets MS?

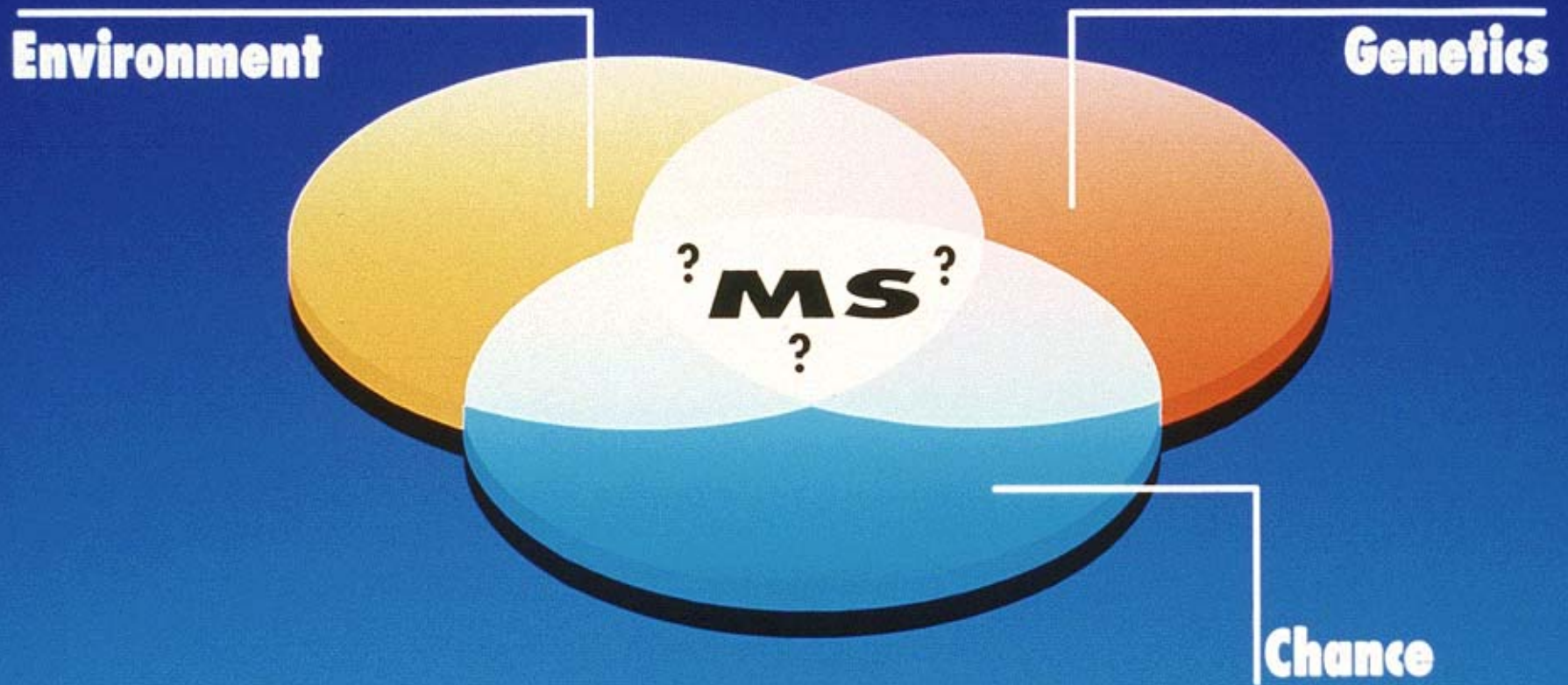
- Female : Male = 3 : 1
- Age Range = 20 - 50 years
- Median Age = 30 years
- Caucasian

Multiple Sclerosis

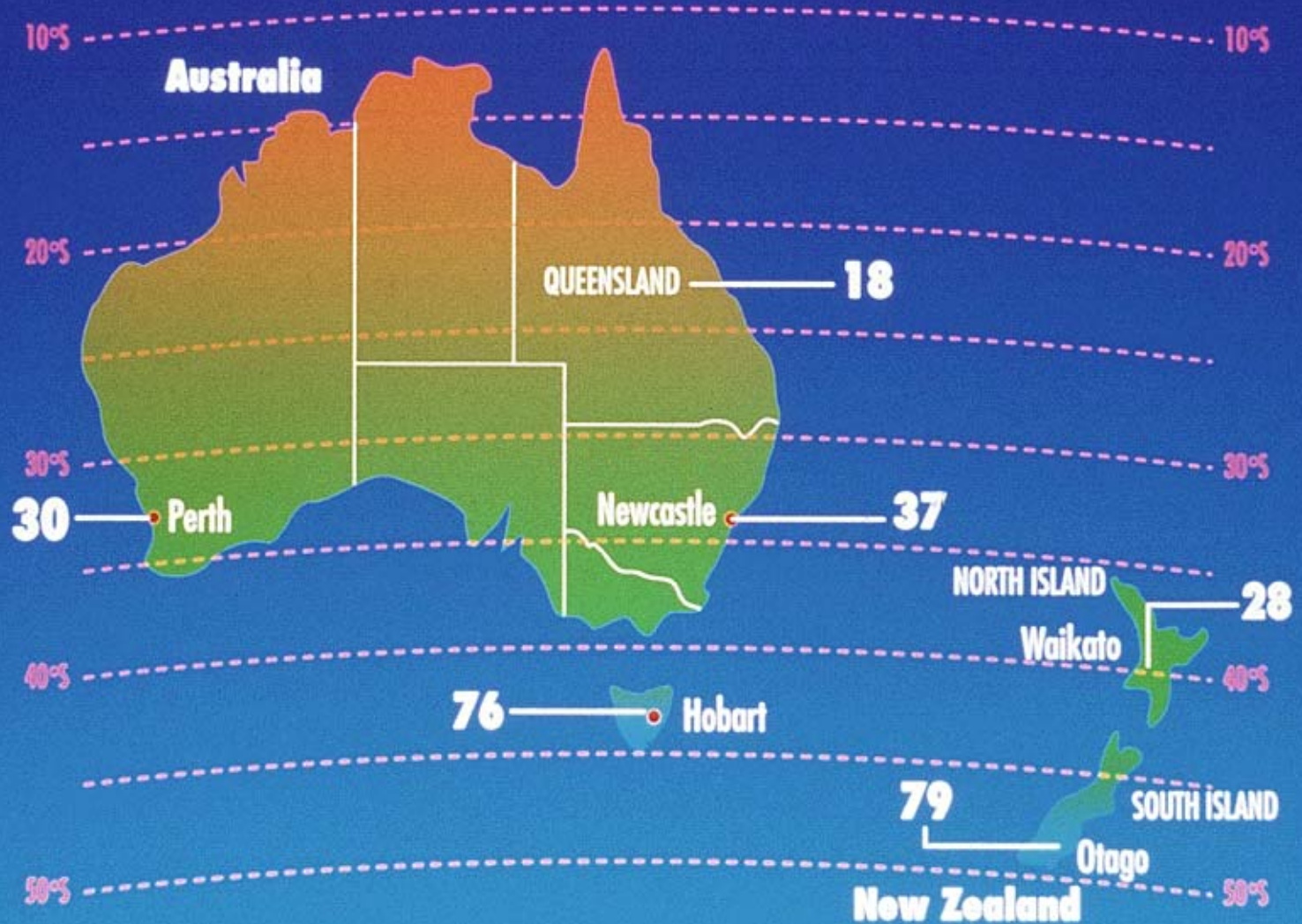
- Disease of the Central Nervous System
Brain, Spinal Cord (white matter)
- Inflammation
- Demyelination
- Axon Degeneration



What factors influence who gets MS?



MS prevalence rates in Australia and New Zealand*



(per 100,000 population)

Symptoms

Blurred or double vision

Fatigue

Problems with speech
and swallowing

Loss of balance or
coordination



Pain

Weakness in arms/legs

Bladder/bowel
dysfunction

Numbness or pins &
needles

Tremor

Heat intolerance


Spasticity

Sexual dysfunction

Cognitive, mood,
behaviour changes

Research Study



- 24 Item Online Questionnaire
 - 295 PwMS (243 females, 52 males)
 - Australia, U.S.A, U.K, N.Z, Canada
 - Focused on
 - Elements of Pre Diagnosis Experience
 - Behaviour in First 12 Months Following Diagnosis
 - Qualitative & Quantative Results
- 

Pre-diagnosis Experience

- Demographics
 - age, gender, country of birth, country of residence, *and* age, occupation, work status, marital status, children, and education level reached *at time of diagnosis*.
- Symptoms
 - first experienced
 - at time of diagnosis
- Number of Exacerbations before Diagnosis
- Time Between Symptoms and Diagnosis
- Suspicion of MS Pre-Diagnosis
- Admission to Hospital Pre-Diagnosis

Post-diagnosis Behaviour



- Seeking of Information
 - **Disclosure of Diagnosis**
 - Social Support
 - Professional Support
 - Employment
 - Immunotherapy
 - Diet/Exercise
 - Spirituality
- 

Disclosure of Diagnosis

- 230 participants disclosed their diagnosis
- 6 themes were identified as reasons for disclosure
 - Why wouldn't you tell everyone?
 - To gain emotional support
 - To ensure correct interpretation of symptoms
 - Due to a sense of obligation
 - I had no choice but to disclose
 - It is no-one's business/I regret disclosing

Why Wouldn't You Tell Everyone?



“It's something that I didn't want to hide. If I did hide it, I would have felt like it was something that had a grasp on me. There is nothing wrong with having MS. ‘I have MS, MS does not have me’ ”

Why Wouldn't You Tell Everyone?



“I feel that through detailing my experiences, I can change the 'face of MS' in a lot of people's minds. I can, through educating others, help alleviate the fears and also reduce the myths associated with MS and other disabling diseases. Knowledge IS power and not only for those with the disease but for those we encounter as well!”

To Gain Emotional Support



“I saw a counsellor at the SA MS Society. They were someone I could talk to about my diagnosis and feelings without feeling guilty. I did not want to upset my family/husband by crying and being depressed all the time.”

To Ensure Correct Interpretation of Symptoms



“I wanted people to understand that my abilities and capabilities would depend on what sort of a day I was having. For example, I was tired of people assuming I was drunk in the middle of the day just because I couldn't walk straight.”

To Ensure Correct Interpretation of Symptoms



“My family all knew about my diagnosis, as it provided them with an answer to why I was always having headaches, loss of movement, and the hearing loss. ...I saw the diagnosis as a relief, as I was beginning to suspect that I had a brain tumour!”

A Sense of Obligation



“Because I had been ill for a long period of time prior to my diagnosis, and I had missed 40 days of work in an eight month period, I felt obligated to tell my employer of my diagnosis once it was made.”

I had No Choice but to Disclose

“At work, I chose to speak with the Chief Social Worker to warn him that I may need to take time off for medical reasons. He asked permission to confidentially advise the Director of Allied Health. Sadly, the DOAH decided to make a public announcement about my diagnosis... and soon, it became public knowledge. This all happened during the 1st month after diagnosis. I then quickly advised my family and friends as in country areas, news travels fast.”

It is No-One's Business/I Regret Disclosing



“In my opinion, my health status is nobody else's business as long as I feel fit. I didn't want people's ideas of me change because of the MS "label", and I want things to stay this way as long as possible. In fact, I was (and still am) quite annoyed that my parents told people about me and my diagnosis without my input. It was not their news to share.”

It is No-One's Business/I Regret Disclosing

“On one occasion when my fiancé was at work, she became upset about my recent diagnosis and asked if she could leave (work), when asked why, she explained the situation and the response was that she had better find another partner because MS turns people into vegetables. That comment did more damage to my relationship than I could ever do. Therefore from that point onwards both my partner and I do not talk about MS to anyone anymore.”

Disclosure of Diagnosis



- Everyone deals with a diagnosis of MS differently
- Pre- and post-diagnosis experience can influence decision to disclose
- Effect of disclosure of MS on psychological health outcomes

Implications for Practice

- Preconceived ideas about ‘what’s best’ for client
- Encourage PwMS to take their time around issue of disclosure
- Consider how others will respond, and prepare for the diverse reactions that may result
- Ensure written material is available
- Contact the MS Society for support/assistance