

Robinson Research Institute

# FAMS: FAmy Planning and Multiple Sclerosis

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history.**

# **Experiences of Family Planning in People Living with Multiple Sclerosis: A Qualitative Study**

## **Management of Reproductive Health in People with Multiple Sclerosis: Understanding the Perspectives of Neurologists and MS Nurses**



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# Rising prevalence of MS

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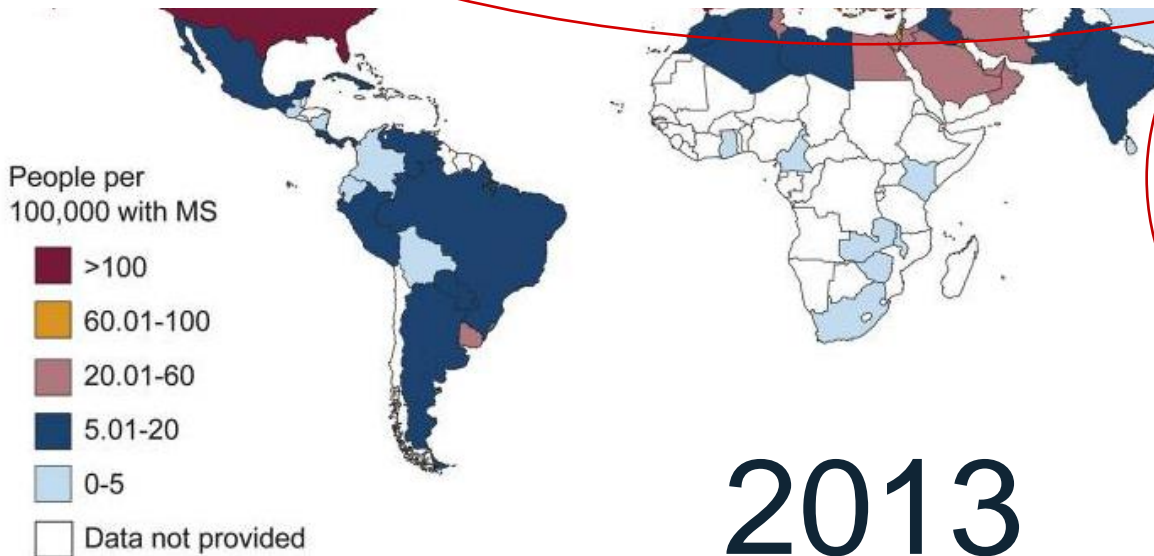
> Mult Scler. 2020 Oct;26(11):1315-1328. doi: 10.1177/1352458519861270. Epub 2019 Jul 26.

## Change in multiple sclerosis prevalence over time in Australia 2010–2017 utilising disease-modifying therapy prescription data

Julie A Campbell<sup>1</sup>, Steve Simpson Jr<sup>2</sup>, Hasnat Ahmad<sup>1</sup>, Bruce V Taylor<sup>1</sup>, Ingrid van der Mei<sup>1</sup>, Andrew J Palmer<sup>2</sup>

Affiliations + expand

PMID: 31347952 DOI: 10.1177/1352458519861270



2013

> J Neurol Neurosurg Psychiatry. 2022 May 16;jnnp-2022-328932. doi: 10.1136/jnnp-2022-328932. Online ahead of print.

## Increasing incidence and prevalence of multiple sclerosis in the Greater Hobart cohort of Tasmania, Australia

Steve Simpson-Yap<sup>1 2 3</sup>, Roberts Atvars<sup>4</sup>, Leigh Blizzard<sup>3</sup>, Ingrid van der Mei<sup>3</sup>, Bruce V Taylor<sup>3</sup>

Affiliations + expand

PMID: 35577508 DOI: 10.1136/jnnp-2022-328932



# Why is this important?

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- What is the family planning experience of Australian people with MS?
- How does MS affect their reproductive decisions?
- Are DMTs safe to use before or during pregnancy or breastfeeding?
- Are there any challenges?
- What happens if someone contemplates starting or enlarging their family?
- What happens if a sexually active individual wants to delay or prevent a pregnancy?

—————→ Decision making ←————



# What is happening in the world


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Check for updates

MSJ Experimental  
Translational  
Clinical

Original Research Article

Family planning  
multiple sclerosis  
approaches

Ricardo Alonso , Li  
María Barbara Eizag  
Adriana Carrá, Anib  
Juan Pablo Pettinic  
Luciana Lázaro, Orla

frontiers  
in Neurology



Contents lists available at ScienceDirect

## Multiple Sclerosis and Related Disorders

journal homepage: [www.elsevier.com/locate/msard](http://www.elsevier.com/locate/msard)



REVIEW

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es

Giovannoni,<sup>2,6</sup>

Systematic Reviews

### Patient awareness about family planning represents a major knowledge gap in multiple sclerosis



Peter Vestergaard Rasmussen<sup>a,\*</sup>, Melinda Magyari<sup>b</sup>, Julie Yoon Moberg<sup>b</sup>, Mette Bøgelund<sup>c</sup>,  
Ulla Fie Appel Jensen<sup>d</sup>, Klaus Gregaard Madsen<sup>d</sup>

<sup>a</sup> Department of Neurology, Aarhus University Hospital, Nørrebrogade 44, Aarhus C DK-8000, Denmark  
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<sup>d</sup> Biogen Denmark A/S, Stationsparken 37, 3rd floor, Glostrup DK-2600, Denmark

Publication status and date: New search for studies and content updated (no change to conclusions), published in issue 10, 2018.

**Citation:** Köpke S, Solari A, Rahn A, Khan F, Heesen C, Giordano A. Information provision for people with multiple sclerosis. *Cochrane Database of Systematic Reviews* 2018, Issue 10. Art. No.: CD008757. DOI: [10.1002/14651858.CD008757.pub3](https://doi.org/10.1002/14651858.CD008757.pub3).

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# What is happening in Australia

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SHORT REPORT

*Multiple Sclerosis* 2008; 14: 701–704

**The motherhood choice: Themes arising in the decision-making process for women with multiple sclerosis**

M Prunty<sup>1</sup>, L Sharpe<sup>1</sup>, P Butow<sup>2</sup> and G Fulcher<sup>3</sup>

Narrative review

**Family planning, antenatal and post partum care in multiple sclerosis: a review and update**

Anneke Van Der Walt<sup>1,2,3,4</sup>, Ai-Lan Nguyen<sup>2,4</sup>, Vilija Jokubaitis<sup>1,2,3</sup>





# What is happening in the Australian contemporary practice?

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**Challenges**

**Time**

**Resources**



# Experiences of Family Planning in **FAMS** People Living with Multiple Sclerosis: A Qualitative Study

**Aim:** To understand the experiences of women and men of reproductive age with MS in relation to family planning to better support them in decision making.

**Methods:** Qualitative, semi-structured, one-on-one interviews (virtual, face-to-face or phone). The transcripts were analysed using thematic analysis, adopting a phenomenological approach.

**Recruitment** via: Australian MS organisations (MS Australia, MS PLUS, MS SA & NT, MS QLD), FB group for Australian mothers with MS.



# Findings – Participant recruitment

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**Total: 22**

**Female: 19**

**Male: 3**



# Findings



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Table 1. Participant characteristics

Age		Gender		Type of MS	Year of diagnosis		Children		Setting		Geographical area		
Range		Female	Male	RRMS	Pre 2011	Post 2011	Yes	No	Public	Private	Urban	Rural	Regional
27-49		19	3	22	6	16	8	14	3	19	15	1	6

## Participants who have children

Pregnant	Breastfeeding	IVF/ART	Miscarriages	Abortions
4	5	7	6	1

## Number of children post diagnosis

0 children	1 child	2 children	>2 children
0	4	3	0

# Findings



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**Table 2.** Emerged themes

Theme	Subthemes
Reproductive Planning	Discussing pregnancy intention
	Involvement in decision-making on reproductive matters
Reproductive Concerns	Passing the disease to the offspring
	Reproductive effects of DMTs
	Disease progression and management
	Coping as a parent
Information Awareness and Accessibility	Adequacy of information
	Conflicting information
Trust and Emotional Support	Continuity of care
	Engagement with peer-support groups



# Participant's voice



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## Theme 1: Reproductive Planning

*"I don't think they asked me that [pregnancy], I think I would mention to them about having children ... but I don't think they would have asked me if I was interested in having children." F*

*"I was told at the very...by my neurologist 'You have to make your own decision about the medication', I was like 'I don't have the level of expertise that a specialists has'." F*

*"[neurologist's name] would like me to be stable for a few years before I do decide to have children." F*

## Theme 2: Reproductive concerns

*"Issues around the likelihood of a baby/offspring developing MS has been a common concern. Call it guilt or hyper vigilance, the idea of passing this condition on, causes big emotionally loaded questions." F*

*"I am a little bit worried about the disability factors and things like that." F*

*"I was worried that, the medication might have done something to trigger infertility." F*

# Participant's voice



**FAMS**

## Theme 3: Information awareness and accessibility

*"I just don't feel that information is readily available, and nobody really shares it with you." F*

*"Maybe the information that you need is not always as accessible...I find the information they might present about a topic like this [MS and family planning] to be really kind of just skimming the surface, and not really getting into a lot of detail." M*

*"I think that's one of the facts that when you get the information from the neurologist and then with the interaction with other people via social media, a conflict is created let's say." F*

## Theme 4: Trust and emotional support

*"I always referred back to my neurology team. They were the ones looking after me and the obstetric team, or the paediatric team at the hospital..." F*

*"Whenever I'd spoken to them [neurologist] about my concerns with MS and pregnancy and what it could mean for the baby and I, things like that, they've always been really reassuring..." F*

*"For the most part, I feel like it's a positive experience to talk to people who are like me but, you know, it can also be really hard. So, it just depends on how I'm feeling on the day or, you know, how advanced someone might be in their disease." F*

# Management of Reproductive Health **FAMS** in People with Multiple Sclerosis: Understanding the Perspectives of Neurologists and MS Nurses

**Aim:** To identify the role of neurologists and MS nurses in supporting family planning for people with MS.

**Methods:** Qualitative, semi-structured, one-on-one interviews (virtual, face-to-face or phone) up to 20 HCPs (neurologists, MS nurses).

**Recruitment** via: Australian MS organisations (MS Australia, MS SA & NT, MS QLD) Professional Associations (ANZAN, MSNA).



# Findings – Participant recruitment

FAMS



Total: 19  
Neurologists: 9  
MS Nurses: 10



Table 2. Participant characteristics

HCP	Gender		Years of experience			Patients per week				Setting		
	Female	Male	0-10	11-20	>20	<1	1-5	6-10	>10	Public only	Public and private	Community based
Neurologists	6	3	3	2	4	1	0	3	5	5	4	0
MS Nurses	9	1	6	4	0	0	1	2	7	6	1	3
Total	15	4	9	6	4	1	1	5	12	11	5	3

# Topics of discussion

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1. Experience in managing family planning/reproductive issues in pwMS
2. Utilisation of available resources such as professional guidelines/recommendations for reproductive health and MS
3. Model of care or service delivery
4. Opportunities to improve reproductive health care and family planning in pwMS

# Preliminary findings



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Topic	Neurologist	MS nurse
Barriers discussing family planning	Time, patients' background, lack of local support resources	Time (mixed reports), patients' background, lack of local support resources
Information sources	Journal articles, discussion with peers	Product information (DMTs), discussion with peers
Contraception discussion	Mixed/rarely proactive	Mixed/more comprehensive
Pregnancy/reproductive intent discussion	Differences in prescribing DMTs, management of MS prior to pregnancy	Management of MS prior to pregnancy
Engagement with other HCPs (i.e., GPs, Obs etc.)	Interdisciplinary approach is desired but not often feasible. Predominately Obs and fertility specialists and less engagement with GPs	Interdisciplinary approach is desired but not often feasible. Proactive communication, mostly connected and engaged with other HCPs



# Key findings-conclusion



**FAMS**

- MS patients want neurologists and MS nurses to engage them in conversation about pregnancy intention
- MS patients express a range of reproductive concerns about MS and its treatment
- Improved information and services related to MS and family planning are required
- Peer engagement and support on reproductive matters may confer emotional benefit
- Engaging men of reproductive age presents challenges

# What is Next

REDCap Consumer Online Survey:

“Understanding the experiences of people living with multiple sclerosis concerning family planning: An online survey”

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# Acknowledgments



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## MS Organisations: Professional Associations:

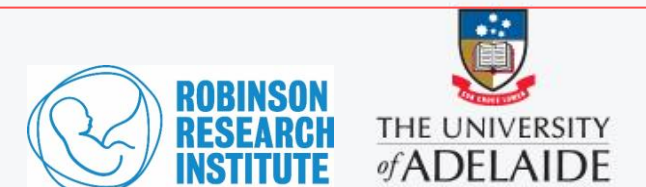


**MS Nurses Australasia Inc**



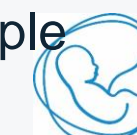
- **Participants**
  - People with MS
  - MS nurses
  - Neurologists

- **Supervisors**
  - A/Prof Luke Grzeskowiak
  - A/Prof Alice Rumbold





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