

Participant information Sheet:

‘Parents’ experiences of a Multiple Sclerosis (MS) diagnosis in their young adult sons/daughters.

An interpretive phenomenological study’

You are invited to take part in the above study. This research is being conducted as part requirement of my Masters in Health Sciences (Nursing Education) programme at National University of Ireland, Galway. Please take some time to read this information sheet and to consider your participation in this study.

What is the aim of this study?

Multiple Sclerosis is the most common neurological disorder in young people in Ireland, specifically across the ages of 20-40 when initial diagnosis occurs. Research is plentiful with regards to the needs and experiences of individuals with MS; however, little has been done to consider the impact such a disease has on the parents’ of a young adult. The aim of this study is to explore parents’ lived experiences of their young adult sons/daughters MS diagnosis.

Who can take part?

Parents’ of a young adult aged 20-40 with a diagnosis of MS in Ireland can take part in the study. It does not matter how long your adult son/daughter has been diagnosed or at what stage of MS they are to participate in the study. Both or one parent can take part in the study and English must be your primary language to facilitate natural conversation.

What will the study involve?

You will be asked to partake in a one to one private and confidential interview with the researcher, on a day, time and location most convenient for you. Interviews should last no more than 60 minutes and will be audio recorded for data purposes.

Will your participation remain confidential?

Yes, all material, notes and tapes will be kept confidential, and stored within a locked cabinet, which only the researcher will have access to. This material will be kept for a period of 5 years, before being destroyed. No identifiable information relating to you will be made available within the written study. All participants will be referred to using pseudonyms and will remain anonymous.

Why should I take part?

Your participation will contribute to exploring the impact MS has on the lives of the parents' and how they experience an MS diagnosis for their young adult son/daughter.

Are there any risks?

Given that the aim of this research is to explore parents' lived experiences of their young adult sons/daughters MS diagnosis, many sensitive issues can arise and cause potential distress for the parents involved. The researcher will ensure to be observant of both verbal and non-verbal cues expressed by you and if issues should arise I will not probe further into upsetting issues. You will be allowed the freedom to choose whether you wish to discuss a sensitive issue or not and your right to refuse participation at any stage of the study will be respected. Time will be allocated for debriefing at the end and you will have the opportunity to ask questions. A written information sheet will be provided on conclusion of the meeting. Contact details for MS Ireland will be provided should you require additional information or support services.

What should I do next?

If you are interested in participating in this study, please complete the enclosed consent form and return to me within the stamped addressed envelope provided. On receipt of this I will make contact with you to arrange a time suitable for you for interview.

What if I no longer want to participate in the study?

You have the right to refuse participation and the right to withdraw from the study at any time, regardless of consent being signed and without a need for explanation. There will be no penalties issued for withdrawal from the study. If you wish to withdraw from the study please just let me know via email or phone.

Where can I find out more information about this study?

You can contact me by email at c.omeara7@nuigalway.ie or by phone on 087) 2251914.