

Participant Information Leaflet

Study Title

Exploring Social Isolation, Loneliness, and Social Asymmetry as predictors of Complex Post-Traumatic Stress Disorder in Multiple Sclerosis

Researcher name

Gary Treacy

Researcher Supervisor (s)

Prof Andrew Coogan, Department of Psychology, Maynooth University

Dr. Philip Hyland, Lecturer, Department of Psychology, National College of Ireland

Dr. Joanna Power, Lecturer, Department of Psychology, National College of Ireland

Introduction

You are being invited to participate in a research study. Before deciding to participate or not in the following study, it is important that you understand why this research is being conducted and what will be involved if you agree to participate. **You should read the following information sheet carefully.**

Why is this study being conducted?

This study is being carried to improve understandings of how people act in response to receiving a diagnosis of a chronic medical illness (i.e., Multiple Sclerosis). Receiving a diagnosis of a chronic illness can be a very stressful life event for many people. It is common to see a large amount of different reactions among people who experience this kind of stressful event in their life.

This study is interested in evaluating if posttraumatic stress is common among individuals who have been diagnosed with a chronic illness. Additionally, this study will consider how factors such as loneliness and/or social factors such as social isolation can influence how likely a person is to experience symptoms of posttraumatic stress following a diagnosis of a chronic illness.

Who is organising and funding this project?

I (Gary Treacy) am currently a student of Maynooth University and the following research project is the main component of my PhD programme in psychological research. The subsequent project will be carried out under the supervision of my supervisors; Prof. Andrew Coogan, Head of the Department of Psychology in Maynooth University; Dr. Philip Hyland, Senior Lecturer at the National College of Ireland and Dr. Joanna Power, Lecturer at the National College of Ireland.

Why am I being asked to participate?

You are being invited to participate in the proposed study as the research project has been approved by the ethics committee of NUI Maynooth and MS Ireland have agreed to share details of the study in accordance with their Protocol for Researchers.

Voluntary participation – Do I have to participate?

No, participation in this study is entirely voluntary. MS Ireland has agreed to include the study in their monthly eNews, as well as their website and social media channels.

For individuals wishing to partake, you will be given a copy of this information leaflet for your personal records and, asked to sign a consent which will express your intention to take part in the subsequent research project.

What will happen if I agree to take part – what is involved?

Participants would be required, on one occasion, to complete a questionnaire booklet containing numerous psychological measures. The duration of completing the questionnaire booklet is approximately 20 to 30 minutes, however the researcher is aware that some participants may require additional time to complete the survey as a result of their medical condition; therefore, no time limit will be imposed for survey completion.

Will participation in this study affect my current treatment?

Participation in the study **will in no way** affect your current treatment.

What are the benefits of participating in this study?

There are no direct benefits from participating in this study. Your participation will however support efforts in helping to understand the psychological responses and individual experiences of people diagnosed with a chronic/life threatening illness.

What are the risks?

Should any individual experience any distress during participation of this study, MS Ireland has provided contact details for the MS Information Line and a list of regional offices on the Participant Information Sheet. <http://www.ms-society.ie/pages/what-we-do/contact-us>

Will my participation remain confidential?

Once you agree to participate, all information collection and responses to questionnaires will remain totally confidential. The proposed project will use the guidelines of the Data protection Acts of 1998 and 2003 for procedures concerning the handling, processing, storage and subsequent destruction of all participant data.

Please be aware that in some situations, the confidentiality of collected data and records may be overruled by courts in the event of legal action or as part of an investigation by lawful authority. In the likelihood of the aforementioned circumstances, the University will take all reasonable steps within law to ensure that confidentiality is preserved to the utmost extent.

Where can I receive further information about the project?

If you require further information regarding any aspect of the proposed study now or at any time in the future, please contact: ***Gary Treacy on 087-6511659*** or alternatively contact ***MS Ireland on 01-6781600***. If you require information relating to specific health concerns, please contact your resident ***Consultant*** or ***Family Doctor***.

Thank you for taking the time to read this sheet