

Research Project Information Sheet



Barriers and Facilitators to Paid Work for Australians Living with Myasthenia Gravis

Ethics Approval Number: S242004

Research Team Contact Details

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Project Description

The purpose of this research project is to explore the impact of Myasthenia Gravis (MG) on people's ability to participate in and maintain paid work. You are eligible to participate in this research if you live in Australia, have a confirmed diagnosis of MG and were working when you first developed symptoms of MG. People who live outside Australia and/or had already retired when they first developed MG symptoms are excluded from this study.

What is the purpose of this research?

The aim of this study is to identify:

- The barriers and facilitators for people living with Myasthenia Gravis to engage in and maintain paid work.
- How personal, environmental, and job-related factors play a part in someone's ability to participate in and maintain paid work.

- How someone's impacted ability to engage in paid work affects their quality of life, specifically within the Australian Myasthenia Gravis population.

Participation: What will I be asked to do?

If you agree to participate in this research project, you will be asked to complete an anonymous online questionnaire about Myasthenia Gravis (MG) and its impact on your ability to participate in and maintain paid work.

The survey will take approximately 30 minutes to complete. The survey will ask questions such as:

- How your MG symptoms affect your ability to participate in paid work.
- How the type of job and associated roles and responsibilities you had prior to your diagnosis influenced your ability to continue your paid work.
- How your MG diagnosis has impacted your ability to engage in paid work and how that has affected your quality of life.

Participation is entirely voluntary. If you don't wish to take part, you don't have to. All results will be combined and analysed together, and no individual will be identified. Once submitted, your survey answers will be transferred and stored anonymously as a computer file.

Consent: How do I agree to participate?

Completion of the survey will indicate your willingness to be involved. You can exit the survey at any stage. However, once submitted, all data is anonymous, so it will not be possible to withdraw your data.

Risks and Benefits

Although there won't be any direct benefits to you for completing this survey, it is hoped that the findings will be used to help develop future resources to support those diagnosed with MG in being able to participate and maintain their employment throughout their working lives. Revisiting the loss of work may result in some psychological distress and/or you may become fatigued over the course of completing the survey. If any topics of the survey lead to feelings of distress and/or are upsetting, you can contact support services including Beyond Blue (1300 22 4636) or Lifeline (13 11 14). People with MG do experience excessive fatigue

so to address potential fatigue, you will be able to complete the survey with breaks over an extended period of time.

Privacy, Confidentiality and Results

Any data collected as a part of this research project will be stored securely as per UniSC's Research Data Management Procedures. All comments and responses will be treated confidentially unless required by law. The results of this research project may be presented at external or internal conferences or meetings, or by publication. If you would like a summary of findings of this research project, please contact the Chief Investigator (listed above).

Concerns or Complaints

If you have any concerns or complaints about the way this research project is being conducted, you may raise them with the Chief Investigator (listed above). If you prefer an independent person, you may contact the Chair of the UniSC Human Research Ethics Committee: telephone (07) 5430 2823; email humanethics@usc.edu.au).