

Carers of people with AMD needed for new study

Macular Disease Foundation Australia is partnering with the University of Sydney and Carers NSW to conduct research into improving the emotional wellbeing among family carers of people with age-related macular degeneration (AMD).

The Foundation is seeking participants for this research. Participants will receive a program that is aimed at improving a family carer's wellbeing, and reduce stress and burden by enhancing the carer's management of negative emotions such as anxiety and sadness.

Why is this research being conducted?

Research suggests that caring for family members with vision loss can be challenging and may result in the carer feeling stressed and with increased risk of health problems. Family carers also often exhibit higher than average levels of depression, financial strain and social isolation than the average Australian. This new study is designed to implement and evaluate a program to improve a family carer's wellbeing.

What does this study involve?

This program involves:

- mail-delivered training package - this delivers practical self-help strategies, which are designed to help carers better adapt and cope with caregiving duties
- telephone-delivered group counselling sessions conducted by Carers NSW, allowing carers to explore the impacts of caring and share their experiences
- education on available community services/resources, financial benefits, and respite services

Who can participate?

To be eligible to participate in the research study, carers must meet the following requirements:

- Be directly involved in helping a person with age-related macular degeneration (AMD) or be directly affected by the person's eye health condition
- Be located in NSW
- Be over 18 years of age and care for a direct family member (eg parent, spouse, partner, or sibling) with AMD
- Be fluent in English
- Be available to participate per the study requirements

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What is required for the study?

It is important that the study participants be available to undertake the program which in summary is:

- A 10 week program for a minimum of once per week, plus a 6 and 12 month follow-up

If you agree to participate in this study, this is what will happen:

- You and the person you care for will be asked to complete an initial questionnaire that will take about 45 minutes to complete. This will involve answering questions regarding your caregiver duties, general health status, and quality of life.
- You will then be randomly assigned to one of two groups to either receive the training program, or a control group which does not require program participation.
- For those assigned to receive the program, it will run over a period of 10 consecutive weeks. Each fortnight you will need to complete a study module and each alternate fortnight participate in a TeleLink phone session with Carers NSW.
- All participants, whether receiving the program or in the control group, will be asked to complete the initial questionnaire and participate in the 6 and 12 month follow-up.
- Those assigned to the control group at the beginning will be given the option of receiving the caregiver support service at the completion of the project in around 12 months time.

Who is conducting this study?

The study is being conducted by Associate Professor Bamini Gopinath in the Centre for Vision Research, Westmead Institute, University of Sydney, in collaboration with Macular Disease Foundation Australia and Carers NSW.

What to do if you wish to participate?



If you are interested in participating in the study or would like more information, please contact Macular Disease Foundation Australia on 1800 111 709.