

## **The experiences of caregivers and recipients of support and assistance for AMD**

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There has been very little research looking at the experiences of people who support someone living with macular degeneration. Research carried out with carers of people with other long-term conditions such as dementia, diabetes and survivors of stroke suggests caring can have a considerable impact on the partners, relatives or friends who care for them. There are many different forms of support including emotional and practical support, information and advice.

Our initial investigation into the extent to which people with macular conditions received support related to their eye condition was undertaken in the Macular Society 2013 survey. This survey found that 845 respondents (54%) reported that someone provided unpaid care, support or assistance to them because of their macular condition. Of these, 47% reported receiving support for 7 hours or more a week. However little is known about the impact of providing this support on the carers themselves or those with macular conditions for whom they care; we designed a follow-up study to investigate this.

We asked Macular Society members who were the respondents to the Macular Society 2013 survey, to indicate their interest in participating in follow-up research. For this initial follow-up study we selected only those respondents who had age-related macular degeneration (AMD). After applying this inclusion criterion this left 138 members who had provided their own and their carer's contact details.

Questionnaire packs were posted separately to the members with AMD and their carers in October and November 2015. Telephone assistance with survey completion was offered.

Members were asked how much difficulty they have carrying out everyday tasks (e.g. housework) and if they receive help with these tasks. Additionally the Daily Living Tasks Dependent on Vision scale measured the extent to which their AMD impacted on vision-related tasks. We added questions on current driving status and whether their carer drives them to places.

Carers completed the Caregiver Reaction Assessment. This questionnaire explores the impact of providing support on various aspects of life (e.g. impact on finances, daily schedule, health). The questions cover both positive and negative reactions to providing support.

All respondents were asked to complete a measure of well-being (W-BQ16). Two questions assessing quality of life were included from the MacDQoL measure of macular-disease specific quality of life, and were adapted to be relevant to the carer. This information was collected alongside demographic information (e.g. age, gender), details about the AMD including any treatment for AMD, and questions on general health e.g. any other long-term health conditions.

Further information was collected on the support received/provided (as applicable), for instance: an estimation of the average number of hours a week of support received/provided, if anyone else assists with providing support, the length of time respondents have been receiving/providing support associated with AMD, and the relationship between the person with AMD and the carer.

We received 73 completed questionnaires from person-with-AMD/carer pairs. Those who completed the questionnaires could volunteer to take part in one-to-one telephone interviews with the lead researcher. Of these, we purposively sampled 12 person-with-AMD/carer pairs to interview. This was to ensure

that we would be talking to people with a range of different experiences.

The interviews are exploring the topics raised in the questionnaires in more detail. Interviewees can raise new points which help us to get an overview of the impact of receiving/providing support for someone with AMD. An important focus for the interviews is to understand how best to support carers in their role, whilst also maintaining the independence of the person with AMD as much as possible.

Analysis of the questionnaire and interview responses is underway. The findings from both research studies will be used to develop services that may be needed, to inform Macular Society campaigns and to help inform future research.