AMD: Care recipients and their caregivers

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Previous research has only looked at how caring for people with wet age-related macular degeneration (AMD) affects caregivers. We studied caregivers and care recipients.

People with AMD completed questionnaires about how much difficulty they had with ‘everyday tasks’ like preparing meals, and ‘vision-dependent tasks’ such as using kitchen appliances. Caregivers told us how providing support affected their finances, daily schedule and health. Both told us about their wellbeing and macular condition, and general health.

The main findings were:

- Caregivers who cared for people in poorer health had less positive experiences of providing care.
- Caregivers who felt less positive about their caring role had worse wellbeing and health, but this didn’t affect the wellbeing of the person they cared for.

The results might reassure people with AMD that the level of difficulty they experience with vision-dependent tasks does not directly impact their caregiver’s wellbeing, health or feelings about providing support.

When we interviewed eight caregiver/recipient pairs in more detail, they told us that living with AMD is a shared experience. They spoke about changes in lifestyle and roles, managing their independence, difficulties in getting professional help and accepting help from family and friends.