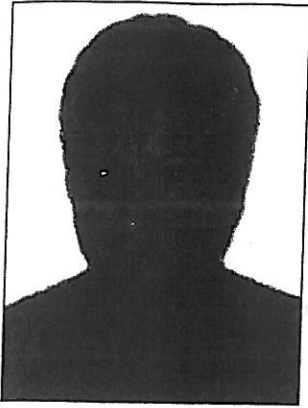


Researching 'Quality of Life'

by **Dr Jan Mitchell PhD**
and **Professor Clare Bradley**



Dr Jan Mitchell is a Trustee of the Society sitting on Council. She works as a research psychologist at Royal Holloway, University of London, where she

gained her PhD for research into psychological well-being and quality of life in macular disease. Her research interests continue to be in the field of macular disease.

It is increasingly accepted that protecting or improving quality of life is an important goal in the treatment and management of medical conditions and that the impact of treatment on people's quality of life should be measured in clinical trials of new treatments and in routine clinical care. In most medical conditions, objective measures of disease or impairment (such as blood glucose control in diabetes or size of scotoma in macular disease) do not adequately reflect the impact of the condition on an individual's quality of life. Even subjective measures, such as functional status (e.g. how well a person judges he or she can read normal print or handle money), do not effectively capture the experience of living with a condition

such as MD. The health psychologists in our team take the view that, to measure quality of life, we need to consider aspects of life of relevance to the individual concerned and measure both the impact of the condition on each aspect of life and the importance of each aspect of life to their quality of life. The University of London team at Royal Holloway has followed these principles in the development of quality of life measures for a number of medical conditions, including MD.

During the year 2000, Professor Clare Bradley and Dr Jan Mitchell designed an individualised quality of life measure for use with people with MD. Members of three Macular Disease Society (MDS) local groups contributed to the design work. The new questionnaire (the MacDQoL) was pilot-tested by post with the help of members of the Society, who were randomly selected from people who had previously completed the MDS Questionnaire and had volunteered to help with further research. A manuscript reporting the design of the measure has been accepted for publication in an academic journal (*Quality of Life Research*) and will be published soon. The MacDQoL has been adopted by a pharmaceutical company for use in an international clinical trial of a potential treatment for wet MD. The questionnaire was translated into 17 languages for the purposes of the trial. Data from the trial will be used to investigate the reliability and validity of the MacDQoL. Some refinement of the measure may follow. The questionnaire will be

shortened if possible without losing important information. In another study that has recently started in Nottingham, the MacDQoL measure is being evaluated outside a clinical trial. This study will include an investigation of the MacDQoL's responsiveness to change in severity of MD over a period of one year. People with both wet and dry MD are participating in the study and they will have a wide range of severity and duration of MD. It is anticipated that this work will demonstrate the MacDQoL's suitability for use with people with all kinds of MD, not just those with wet MD who are being included in the clinical trial that is using the MacDQoL.

During 2003, further work on the MacDQoL was carried out with the help of members of ten MDS local groups. The study investigated whether MacDQoL scores were comparable when different methods of completing the questionnaire were used (pen and paper or telephone interview). In addition, the acceptability of the measure to respondents and its sensitivity were compared with that of another so-called 'quality of life' measure. The other measure was a 'utility' measure used to calculate quality adjusted life years known as QALYs. QALYs are used by health economists to indicate the impact of medical conditions on quality of life. QALYs have been adopted by the National Institute of Clinical Excellence in its evaluation of new treatments, including the recent appraisal of photodynamic therapy for the treatment of wet MD. However, there is good reason to believe that QALYs provide little indication of quality of life in people

with MD and this has been investigated alongside evaluating the MacDQoL. When the findings are published, it is hoped to present summaries in the Society's Digest or Side View.