

Mitchell J and Bradley C. Quality of life in Macular Degeneration: Age-Related Macular Degeneration Alliance International (AMDAl) White Paper. 2006 International Society for Quality of Life Research meeting abstracts [www.isoqol.org/2006mtgabstracts.pdf] The QLR Journal, **A-68**, Abstract #1728.

Oral presentation at ISOQOL 2006, Lisbon, 12-14th October.

Abstract 1728

QUALITY OF LIFE IN MACULAR DEGENERATION: AGE-RELATED MACULAR DEGENERATION ALLIANCE INTERNATIONAL (AMDAl) WHITE PAPER

Jan Mitchell, Clare Bradley, Psychology, Royal Holloway, University of London, Egham, Surrey, United Kingdom

AIMS: The AMDAl sponsored us to review the literature and prepare a White Paper on QoL in macular degeneration (MD) with a view to increasing awareness of MD, reducing its impact and improving services for people with MD worldwide. **METHODS:** A systematic review was conducted using electronic databases, conference proceedings and key journal hand search checks. **RESULTS:** MD, a chronic, largely untreatable eye condition, is the most common cause of blindness in the Western world. Shock of diagnosis, coupled with lack of information and support are a common experience. Incidence of depression is twice that found in the community-dwelling elderly. Some people feel suicidal. MD threatens independence, especially when comorbidity exacerbates functional decline. Rehabilitation, including low vision aid (LVA) provision and training, peer support and education, can improve functional and psychological outcomes but many people do not receive services likely to benefit them. Medical treatments, available for only some types of MD, can improve function but most limit progress of MD, at least for a time, rather than cure. The White Paper considers difficulties associated with inappropriate use of health status measures and misinterpretation of utility values as QoL measures: evidence suggests they have poor validity in MD. **CONCLUSIONS:** There is considerable evidence for the major damage done to QoL by MD which is underestimated by health status and utility measures. Medical treatments are limited to a small proportion of people. However, much can be done to improve QoL by early diagnosis of MD with good communication of prognosis and continuing support. Support could include provision of LVAs, peer support including MD Society groups, education and effective help in adjusting to MD. The value of such provision is unlikely to be demonstrated by health status or utility measures. It is vital that appropriate measures of visual function and QoL be used in building a sound evidence base for the effectiveness of rehabilitation and treatment.