

SIDE VIEW

THE VOICE OF THE MACULAR DISEASE SOCIETY

No 49 April 2000

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MD. SOCIETY QUESTIONNAIRE:
Members' experiences of MD and its impact on their quality of life.

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Last year, 1421 members returned questionnaires about their experiences with MD. Their average age was 76 years. Few people had heard of MD before diagnosis and the study shows that people want to have more information in the early stages. Many people may have been less anxious and more able to adjust to MD if they had had information about low-vision aids, local support services and the nature and development of the condition.

When asked about types of MD, a higher proportion of members have wet MD than the overall population of people with MD. Also a larger proportion have both eyes affected than reported in other research. This suggests that some people may be joining the Society when their vision becomes seriously impaired. Half did not know what type of MD they had and more women than men did not know. This may be because women in this age group are more reluctant than men to ask questions, or because doctors give more information to men.

Many members were dissatisfied with their contacts with health professionals. About half thought the eye specialist who diagnosed their MD was not interested in them as a person, though about half were happy with their consultations at diagnosis. Amongst those not satisfied the most common criticism

was the attitude of eye specialists. Their manner was often described as brusque, dismissive, uncaring or patronising and there were complaints about the lack of information. Specialists have a difficult job, as they have bad news for which patients are often completely unprepared. At present there is hope of treatment for only a small number of people with MD. The word 'blind' has heavy emotional overtones, and may leave the patient in shock. Specialists may feel they should keep the interview short, but by giving information about the possibility of help from low-vision aids, they can give positive, practical support and reassurance.

13% of members said they thought their GP was very well informed about MD, but more than twice as many thought their GP was not at all well informed. Over a quarter thought their GP was very helpful and supportive, but a similar number thought he/she was not at all helpful. Many people appear to have no contact with their GP about MD and although one might expect them to be a source of ongoing support, many members did not have help and support from their GP. People who had unsatisfactory experiences with health professionals had poorer well-being than those who were satisfied. These findings suggest that a more supportive approach may benefit people with MD in the long term. Specific problems with the provision of information were highlighted. A quarter of members were not told the name of the

condition and a few were wrongly told they would go completely blind as a result of MD. Over three quarters were told that MD was part of the ageing process, which does nothing to enlighten or reassure them. Although MD is more frequent in older people, it is not an inevitable feature of ageing. It was disturbing to read reports by some members of the lack of respect and courtesy shown to them, which they felt was due to their age.

The vast majority of members were told that 'nothing can be done' for their MD. Although that is often the case medically, it is essential to inform people that a great deal of support is available to help them adjust and live with their MD. Many experienced distressing emotional reactions to being told that nothing could be done, including 54 people who said they felt suicidal. The study shows the importance of giving people adequate and accurate information together with ongoing support.

Low-vision aids (LVAs) were found to be useful by 75% of members who were registered partially sighted or blind and most had been shown how to use them. Amongst those who did not find LVAs useful, a smaller percentage had been shown how to use them. Only 57% of those registered partially sighted or blind had been visited by a rehabilitation officer. Provision of rehabilitation and LVA training were associated with increased well-being.

Visual changes were common, with 78% saying they had experienced such changes as pulsating lights, blurred vision or hallucinations,

which were associated with poorer well-being. Although half had discussed them with health professionals, only 40% of those were offered an explanation and these were not always reassuring and sometimes inaccurate. Being given an explanation may have a beneficial effect, as people might worry less if they were told that visual changes are not a sign that they are going 'round the bend'. It may also help to know that, in most cases, hallucinations will recur for only a limited period.

Lack of communication about hallucinations highlights the need for improved doctor/patient relationships and also the need for more accurate information for patients, for specialist guidelines and continuing education for health professionals

Our thanks go to those members who helped develop the questionnaire and to those who generously completed them. We acknowledge with thanks the advice of Mr Tim ffytche and of Mrs Marion Davies. The valuable database we now have shows the need for improvements in support services and patient care for people with MD and the need for accurate information for both health professionals and patients.

The questionnaire analysis conducted to date points to the need for communication, information and rehabilitation. With increasing numbers of people developing MD there is an urgent need now for action to improve services and facilitate research into the many aspects of MD.

