The MD Patient Charter: An Initiative to Empower Those With Macular Disease

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In an effort to provide hope and help to individuals burdened with the significant physical, mental, and emotional challenges of macular disease (MD), the AMD Alliance International (AMDAI) developed the Macular Disease Patient Charter. The charter, which was unanimously endorsed by 60 member institutions from 23 countries at the AMDAI Annual Congress in May 2008, is a roadmap for the patient life journey, designed to inform patients with macular disease about their diagnosis, their rights as patients with low vision, and the aftercare available to them.

THE FOUR CORNERSTONES

There are four essential cornerstones in this charter: prevention and cure; timely diagnosis; universal access to proven treatment; and holistic care and support.

TABLE 1. THE FOUR CORNERSTONES OF THE MD PATIENT CHARTER

Awareness, Prevention and Cure

People have the right to expect that:

- research into causes and cures is supported by public funding;
- public awareness programs are developed to ensure that awareness of MD as a disease with risk factors is enhanced and action can be taken to reduce risk and future incidence of MD.

Diagnosis

People have the right to:

- a timely and accurate diagnosis from qualified and accredited personnel.
- be treated with dignity and respect, which includes receiving timely, supportive and respectful answers to questions.
- receive, at the time of diagnosis, full and complete information about MD, about potential changes in the life journey ahead, and about how to access nonmedical resources such as vision rehabilitation and counseling.
- bring caregivers and family into doctor's appointments if they so wish.

Treatment

Persons with macular diseases have the right to:

- timely care with best possible approved or authenticated treatments.
- make an informed consent to treatment, which means they must be provided with information to ensure understanding about all approved treatment or disease management options, potential benefits, risks, and side-effects.

Care and Support

People have the right to an optimum standard of care, which includes receiving information about:

- options for disease management, including follow up eye exams and on-going care.
- risk management strategies.
- low vision services and vision rehabilitation, including referral to self-help and professional services such as counseling or other psychosocial services.

COGNITIVE DECLINE AND AMD

Giving up valued activities is associated with an increased risk of cognitive decline in older patients with vision loss caused by age-related macular degeneration (AMD), according to a report in *Alzheimer's and Dementia*.[1]

William Tasman, MD, of Wills Eye Hospital in Philadelphia, PA, and colleagues conducted a 3-year longitudinal study of 206 nondemented patients with AMD.

The investigators found that over the 3-year period 23 patients (14.4%) declined cognitively. Age, sex, education, decline in visual acuity, and number of dropped activities were associated with cognitive decline, and each additional dropped activity increased the risk by 58%, the study said.

Individuals who gave up three activities were 3.87 times more likely to become demented than those who did not relinquish a single activity. Patients who gave up five activities were 9.54 times more likely to decline cognitively.

These results suggest the importance of promoting optimal cognitive and physical health in patients with AMD, the investigators concluded.

1. Rovner BW, Casten RJ, Leiby BE, Tasman W. Activity loss is associated with cogntive decline in age-related macular degeneration. Alzheimers Dement. 2009;5(1):12-17.

Each cornerstone outlines patients' rights and maps the way to improved quality of life (Table 1). All people are entitled to the rights outlined in the charter regardless of age, gender, marital status, ethnicity, religion, sexual orientation, education, and financial status.

Wanda Hamilton is the executive director of the AMDAI. In an interview with *Retina Today*, Ms. Hamilton explained that the AMDAI and its member organizations around the world offer patients a variety of support and education services, ranging from advocacy hotlines and vision screening, to mental health and social services, to orientation and mobility training.

Retina physicians must play a major role in helping AMDAI and organizations like it get the word out to patients about what services are available in their region or country, Ms. Hamilton said. "The charter articulates what patients' expectations are. If retina physicians know what their patients expect from them, such as a referral to aftercare support, it is easier for a physician to effectively manage MD patients," she said. "Therefore, it is critical that retina physicians are familiar with the four cornerstones and help patients access the services available to them."

BROADENING THE TREATMENT PARADIGM

One of the key ways that retina physicians can empower patients with MD to improve the quality of their life is through broadening the treatment paradigm to include referral to aftercare supports and low vision rehabilitation. Rehabilitation includes low vision assessment, adaptive living, low vision devices, vision training, counseling support, benefits advice, orientation, and mobility training.

Aftercare supports, such as professional counseling, help people with macular disease address symptoms of depression, which often plague patients with low vision. Aftercare support services also provide patients with tools and techniques for vision rehabilitation. For example, some patients retain their peripheral vision when they lose their core vision. Facilities that specialize in training patients in how to maximize their peripheral vision through lighting or through a voice- or large-print- equipped computer can help improve the quality of their lives. Additionally, the technique of eccentric viewing or preferred retinal loci trains patients to look slightly away from an object in order to view it peripherally with an intact area of the visual field.

The first step retina physicians must take to ensure that their patients receive professional counseling and/or vision rehabilitation is to learn what aftercare supports are available in their region, Ms. Hamilton commented. "Additional steps could be as elaborate as having aftercare supports available in one's clinic or as simple as making pamphlets available in the office and/or on the Internet that explain what aftercare supports are available," she said. "Ultimately, the AMDAI wants patients to access the aftercare that they have a right to receive, and retina physicians are essential to making that happen."

LONG-TERM GOALS

Currently, low vision rehabilitation services are available in most countries, but systems of delivery, the range of services available, and access to support, treatment, and research for patients with MD vary considerably. This is not enough, Ms. Hamilton said. In the long term, the AMDAI wants governments to establish service level agreements that outline what people with MD are entitled to by virtue of their citizenship.

MD RESOURCES

For information on international and national MD and low vision advocacy organizations, their network of regional affiliates, and aftercare support services, please visit AMD Alliance International <www.amdalliance.org>, Prevent Blindness America<www.preventblindness.org/>, and Lighthouse International <www.lighthouse.org/>. Peer support for your patients is available at Macular Degeneration Support <www.MDsupport.org> and Macular Degeneration Partnership www.amd.org/. ■