

International Low Vision Support Group

NEWSLETTER

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This Month

"Every Patient Can Be An Advocate"

We will discuss ways that patients can advocate for their needs with eye care professionals, other members of the blind and low vision community, family members and friends, and elected officials. By so doing, patients can not only offer a necessary gift to families and communities, but they can reap the pleasures of personal accomplishment and purpose. Listen online at <https://eyesight.org/wp-content/uploads/2024/05/advocacy2.mp3>

Dan Roberts

News & Information

How Can We Be Effective Advocates?

Advocacy for people affected by blindness and low vision is an important and much-needed cause to which we can all relate. Blindness and low vision advocacy means taking an active part in improving treatment, health care, and daily living for those among us who cannot, or do not, always speak for themselves.

Formal training is not required to be an advocate, but the title is usually justified by knowledge, experience, and passion. The cause could be as far-reaching as human rights, education, and poverty, or it could be as simple as speaking out about litter in the neighborhood.

Advocacy is fueled by natural born empathy. The capacity for empathy can be innate, it can be acquired by way of relationships with others, or it can be activated by memories of one's own personal experiences. But it cannot be taught. Having walked in someone else's shoes is the best way to learn it.

We are walking in similar shoes, which means that not only do we have the right to speak out, we have an obligation to do so. I hope this month's presentation will encourage us to speak or act out when opportunities arise that call for it.

The most personal way for us to advocate is to educate family members and friends about blindness and low vision. Here are some important "Rules of Etiquette" that can serve to guide them in their relationships with us:

- **It's not necessary to speak loudly, but please enunciate and give audible cues about your meaning. We may not be able to see your face, and much of a person's understanding comes from reading lips and interpreting facial expressions.**

- **Address us by name. That may be the only way we know if you're speaking to us directly.**

- **Speak to us personally, not through others. Poor vision does not diminish our hearing or our ability to communicate.**

- **Greet us when you enter the room so we know you're there. Just say something simple like, "Hi, Joe. Jane here."**

- **Indicate the end of our conversation when you leave us so we aren't left talking to a floor lamp.**

- **If you think we need help, please ask first. Given enough time, we can do most things by ourselves, so don't assume that your help is necessary or desired.**

- **And generally, never take hold of a white cane or interfere with a guide dog while it's on duty. Doing so is not unlike covering the eyes of a sighted person.**

Unique “GuideMe” Books Offer Free Personal Guidance for People Affected by Retinal Disease

Prevent Blindness, a patient advocacy organization preserving vision and eye health for more than 115 years, continues to give the gift of living well with low vision. Its most recent offerings are the free GuideMe Books for people with age-related macular degeneration and diabetes-related diseases.

Similar to a practicing low vision therapist, online questionnaires first pose questions about the individual’s condition, daily challenges, and available resources. Then, following the model of a professional low vision therapist, they create easy-to-read publications of all pertinent options for maintaining or improving upon an individual’s specific necessities and desires. The books may be read online or saved in portable document format (PDF) for reading offline or printing.

All information is anonymous, collected privately by the individual or the individual’s caregiver, and none of it is stored or shared. The user may also return to the GuideMe site to edit as circumstances change. The book’s biggest asset is that it targets only those areas that pertain to the user, which eliminates frustration and time searching through irrelevant material. To help the reader’s understanding, a large glossary of ophthalmic terms is also included.

The GuideMe books are not intended to replace a low vision therapist, since there is nothing better than human interaction. It is instead meant to be a first step for those who are unable or unready to benefit from low vision rehabilitation.

To learn more about the GuideMe books and to create a personal copy, visit <https://lowvision.preventblindness.org/guideme-apps/>.

Next Month

“Learning to Live with Low Vision”

An individual’s first-person account of the journey from discovery to independence through low vision rehabilitation.