

Sharing Solutions

Spring 2007

A newsletter for
People with Impaired Vision and
Their Support Networks



LIGHTHOUSE[®]
INTERNATIONAL

Staying Informed

Keeping up-to-date in this information age can be challenging. Advances in treatments for eye disease and technology are taking place at record speed. An important priority at Lighthouse International is bringing you the latest information through **Sharing Solutions** and our other free publications, as well as online at www.lighthouse.org. We encourage you to take advantage of these resources.

In this issue, we share the latest information about treating wet AMD — a timely topic, and one that you requested we cover in our recent reader survey.

We also introduce you to “**Living Better at Home: A Guide for People with Vision Loss**,” our national campaign that includes print and online resources promoting independence, safety and accessibility. In addition, we’ve updated **All About Low Vision**, a popular brochure that explains the major causes of low vision, and how vision rehabilitation services can help. Both resources are available free of charge, so order yours today!

Familiarizing yourself with your learning style can be particularly helpful if you lose vision later in life. Your style affects how you process information and can assist vision rehabilitation professionals as they introduce you to new techniques. Do you know what type of learner you are? Find out inside.

Finally, we appreciate your tips for making home life more comfortable, and have included them in “Coast to Coast.” As always, many thanks for sharing!

Carol J. Sussman-Skalka

Carol J. Sussman-Skalka
Newsletter Editor



New Treatments for Wet AMD

By Richard Spaide, MD

What Is Wet AMD?

Wet age-related macular degeneration (AMD) is a term that describes a process where blood vessels and other cells invade the area under the macula, the part of the retina used for detail vision. The invading tissue can leak, bleed and cause scar tissue to form, damaging the macula and causing vision loss.

The most important aspect about wet AMD is that the body wants, and actively tries, to make these blood vessels grow. In many diseases, doctors help the body do what it already wants to do. For example, if you get an infection, your doctor prescribes an antibiotic that works together with your body’s immune system to clear the infection. Once you’re better, you stop taking the antibiotic. Macular degeneration is quite different. Your doctor is trying to oppose what your body wants to do. The body wants to make blood vessels grow, while your doctor tries to prevent that growth. Treatment for wet AMD can suppress the body’s ability to make blood vessels in the eye, but sooner or later the medicine wears off and the body will try to make blood vessels grow again. Then, the treatment needs to be repeated.

If you’re diagnosed with wet AMD, it is a life-changing event. You will need chronic treatment. Currently, there is no cure; however, conscientious follow-up and treatment are usually successful in keeping these blood vessels in check.

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Evolving Treatments

While a cure for wet AMD is not yet a reality, there are now more treatment choices, and the field is changing rapidly. Recommendations made only a few years ago no longer hold today.

For example, doctors previously used a laser to treat wet AMD. Although lasers may sound high-tech, the strategy for their use was fairly simple. The doctor used the laser to burn the blood vessels in order to make them go away. Since the body actively tries to make blood vessels grow, it isn't hard to figure out the problem with lasers — even if a doctor could successfully “cook” these blood vessels, new ones often quickly regrew to take their place. Unfortunately, each laser treatment destroys retinal cells.

The next development used a drug called Visudyne® that specifically binds to blood vessels. When Visudyne® is activated with a special cold laser in a process called photodynamic therapy, the drug damages blood vessels and causes them to close down. In the process, the treatment caused inflammation but not as much damage to the retina as the hot laser. Yet again, the same difficulty exists: blood vessels regrow after treatment. While photodynamic therapy can be repeated without causing too much damage, it does have several drawbacks: it causes some damage to normal tissue, and doesn't work for many subtypes of wet AMD.

To avoid some of the problems with photodynamic therapy, doctors began to use triamcinolone — a corticosteroid injected directly into the eye. Triamcinolone reduces inflammation specifically caused by photodynamic therapy and suppresses the regrowth of vessels. In addition, triamcinolone lasts for up to six months in the eye. Patients treated with a combination of triamcinolone and photodynamic therapy appeared to have better visual outcomes with fewer treatments per year. Unfortunately, triamcinolone has many side effects, including glaucoma and cataract formation.



Macular Degeneration: The deterioration of the macula, the central area of the retina, is the most prevalent eye disease in older adults.

Anti-VEGF Treatments

The need emerged to develop a way to suppress blood vessel growth without causing so many side-effects. The answer came from cancer therapy. Tumors grow, and to grow past a certain size, they need blood vessels to feed them. Cancer research has focused a lot of attention on inhibiting this process. The most important chemical that causes blood vessel growth is a protein made by the body called Vascular Endothelial Growth Factor (VEGF). Various drugs have been developed to block the effects of VEGF so that blood vessel growth can be stopped or, at least, restrained.

Injecting VEGF blockers (anti-VEGF agents) into the eye was a huge breakthrough in treating wet AMD. The first drug used was Macugen®, developed by (OSI) Eyetech, which could only block some forms of VEGF. Patients treated with Macugen® did better than those not having treatment, but they still lost vision. Later development of two closely related drugs, Avastin® and Lucentis® by Genentech, brought macular degeneration treatment to a new level. Patients treated with Lucentis® have a small improvement, on average, in visual acuity. Until now, no other treatment had resulted in a net gain in vision. Some doctors are using Avastin® and,

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while the cost differs, the results to date are very similar. Both drugs are significant advances, producing much better results than no treatment or previous treatment. Lucentis® is FDA-approved for wet AMD. Avastin® is FDA-approved for colorectal cancer and is being used “off-label” to treat wet AMD. Both drugs continue to be evaluated in ongoing clinical trials.

Initial clinical studies used monthly injections of Lucentis® in patients with wet AMD with impressive results. Various strategies are being used to try to reduce the number of injections needed, as monthly treatment is a difficult regimen for patients. We don’t know the right approach for everyone, but we are finding that it’s possible to use less frequent dosing in many patients. About one-third of patients treated will have a significant improvement in vision, which retinal specialists define as being able to read three lines more on the eye chart than before treatment. However, many patients lose more lines than this when they initially develop the disease, so a three line improvement in a minority of patients still isn’t the desired outcome.

What we would like is for a greater proportion of patients to have a greater amount of vision gained. To accomplish this, treatment trials are underway to combine other drugs or treatments with Lucentis® or Avastin®. For instance, the use of Lucentis® with a drug that blocks a factor called Platelet Derived Growth Factor (PDGF) is under investigation to see if the results are better than using Lucentis® alone. Most studies of this type focus on newly diagnosed, previously untreated patients. Another goal is to reduce the number of required treatments. Some new research is investigating various strategies to reduce the treatment frequency, but the visual outcomes of these approaches are not known at present.

It’s important to work with your doctor to stay informed and assess your treatment options. Early treatment is critical. Although the results of treatment are better than ever before, we continue to look for even more promising results in the future. ●

Richard Spaide, MD, is an ophthalmologist with Vitreous Retina Macula Consultants of New York, and is affiliated with the Manhattan Eye, Ear and Throat Hospital.

New Resources Designed with You in Mind

We’re delighted to announce the launch of our national initiative “**Living Better at Home: A Guide for People with Vision Loss,**” made available through an unrestricted educational grant from Genentech, Inc. This campaign consists of print and online resources that promote safety, independence and accessibility at home.

Request Your Free Kit

We have compiled a useful kit with information about: caring for your eyes, normal vision changes due to aging, common age-related eye diseases and their treatments, strategies for living with different eye conditions, vision-friendly home solutions

and tips to share with others. Also included are three helpful products: a signature guide, a bold-tip pen and tactile dots to mark appliances.

Go Online to Order and Learn More

We’ve created a brief video demonstrating the use of adaptive products and techniques to make food preparation safer and easier. And we developed online mini-courses to take you step-by-step through these techniques. Check them out and order your free kit at www.lighthouse.org/livingbetter. Or call (212) 821-9567 for a kit. ●

Coast to Coast: Readers Share Tips to Make Home Life Easier

When you have vision loss, or live with someone who does, there are adjustments for everyone involved. In our last issue, we asked you to tell us about the changes you've made to feel more secure and comfortable in your home. Here's what you had to say.

Getting — And Staying — Organized

The key is getting rid of clutter. And it's often easier said than done. If you need help, ask a family member or friend. Start by going through your closets, cabinets and drawers to remove items you no longer use or need. Once that's done, it's a lot easier to organize what you have. And whatever system you choose, keep it simple so you can find an item when you need it — “a place for everything, and everything in its place.” Make sure to share your plan with family members, housekeepers or house guests.

Here are some things you suggested:

- Designate pantry and refrigerator shelves for specific items by using raised markings or large-print labels
- Differentiate canned goods by using magnetic reusable labels or rubber bands
- Find items more easily by storing them on rotating tiered shelving
- Separate socks, jewelry or paperwork in plastic sealable bags or containers

Using All Your Senses

Don't forget to use your other senses to identify items. For example, jewelry often can be differentiated by feel — shape, stones (smooth vs. faceted), length, etc. Use tactile raised bumps or dots to mark appliance settings. And take advantage of talking products. Other ideas include:

- Place wind chimes or a radio on your patio/porch to keep you oriented outside
- Turn prescription bottles upside down after you've taken your daily dose

Color and Contrast

Many people improve visibility by enhancing color and/or contrast. For example, dining is more comfortable when place settings contrast with tablecloths. And you're less likely to knock over colored glasses than clear ones. Here are some additional tips:

- Outline the plug area of switch plates with a bold marker
- Set off furniture against a contrasting carpet or wall, or make it stand out with contrasting pillows
- Highlight doors by painting frames to contrast with the wall
- Distinguish your keys with the help of different colored nail polish or key covers

Safety

Safety is a top priority for everyone. We received a great deal of feedback regarding throw rugs — some people feel they're a hazard and have discarded them; others find them helpful as landmarks and secure them with tape. Stairways are another hot spot. Readers mark the edges of the top and bottom steps, install handrails and ensure sufficient lighting. One woman feels a lot safer after alternating two different contrasting carpets on her stairway steps. For additional safety tips, order our **free** “Living Better at Home” kit (see page 3).

Popular Products

Readers shared a variety of adaptive products and electronic devices that they find useful:

- ✓ Large-print calendar
- ✓ CCTV to magnify reading material
- ✓ Large-button telephone
- ✓ Computer with adaptive software
- ✓ Talking caller ID and answering machine
- ✓ Voice-activated cell phone
- ✓ Large-screen TV
- ✓ Talking appliances

Thanks for sharing ...

Phyllis Bierdz, Mayslake Village Low Vision Support Group, IL; Ernie Breece, Marion County Eye to Eye Support Group, OH; Betty Cain, Low Vision Support Group Max II, SC; Julia Kleinschmidt, VIP Support Group, UT; John McElheron, The Way Eye See It Support Group, Lakeshore Seekers Peer Support Group, & Eye Am Coping Support Group, MI; Antonette Pickering, IA; Jerry Rosenberg, Macular Disease Association of Boynton Beach, FL; Mary Rumman, Turner Geriatric Clinic Low Vision Support Group, MI; Linda Scribner, League for the Blind and Disabled Support Groups in Angola, Auburn, Decatur, Fort Wayne and LaGrange, IN; Marion Slacke, Focus on Eyes Support Group, NJ; Delores Wussler, Insight Support Group, FL.

Take Part in Our Next Coast to Coast

In the fall, we'll continue our exchange on what you've done to make your life at home easier, safer and more convenient. Use the following questions as a guide at your next support group meeting or during conversations with others.

- What types of lighting help you the most? How do you deal with glare?
- What problems at home are you still trying to solve?
- How have friends or family members been helpful — or not helpful — in making your life at home easier or making their homes "friendlier" for you?

Please respond by October 1, 2007, so your responses can be included in our next issue. Call Carol Sussman-Skalka at (212) 821-9481, or e-mail her at sharingsolutions@lighthouse.org. You can also send letters or tapes to Carol at Lighthouse International, 111 East 59th Street, New York, NY 10022-1202. ●

What Kind of Learner Are You?

By Nancy Paskin, MART, CVRT

While we all use our senses to learn, people usually have a preferred sense or learning style. Educators generally classify learners into three categories: visual; auditory; or kinesthetic, which is a combination of touch and movement. Each of us has a primary way of learning, but we all use a combination of two or all three. Regardless of learning style, in general, we take in a significant amount of information visually.

When you lose the ability to visually confirm information gained through other senses, you may not trust those clues. This can cause you to feel an even greater sense of loss. But if you know your learning style, it can be helpful information for the vision rehabilitation professionals working with you. As they focus on helping you to use alternative techniques, they can adapt their teaching strategies — to make it easier for you to learn and to be more sensitive to how you like to do things. For example, if you're primarily a visual learner, you may find it harder and less satisfying to listen to books on tape and be more inclined to learn to use prescribed magnifiers so you can read more like the way you used to.

Visual learners gravitate to pictures, drawings, reading and taking notes, and may not respond as well to verbal directions. Instructors can integrate a variety of visual aids into your lessons, such as large-print agendas, outlines, drawings and handouts. And they can encourage you to take notes with a bold-tip pen by including larger spaces for writing.

If you're a visual learner, you may prefer to use optical or electronic devices to read or perform other activities using vision, much like you used to. In addition, visualizing faces, places and activities can help with orientation in new surroundings as well as with recalling the steps involved in performing a particular task.

Auditory learners respond best to verbal directions, detailed descriptions and lectures. They may find it helpful to memorize steps

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or procedures as well as to repeat information out loud. These learners will prefer to tape record notes, directions and lectures. Instructors can integrate the auditory style into their teaching by providing a brief explanation of what's coming, presenting new material and then summarizing. In addition, when introducing a new device or product, they can point out the sounds emitted as it is being used.

Auditory learners respond well to talking things through and listening, so that question/answer formats, brainstorming and small group discussions become good teaching tools.

If you're an auditory learner, you will likely find it helpful to verbalize major points, summarize learning tasks and pose questions. You also may be more amenable to using talking products.

Kinesthetic learners prefer to do an activity in order to learn a task or concept. Hands-on experiences and movement keep their interest. For example, while instructors are explaining a new product or device, they can encourage these learners to touch and explore the object at the same time. And kinesthetic learners remember best when they write things down several times.

If you're a kinesthetic learner, you may also like to draw, use a computer to take notes and highlight key points on handouts.

Reality Visualization

All learners, especially those with vision impairment, will find that using their memories to visualize activities performed prior to their vision loss can improve function. Reality visualization involves creating a mental picture, map or scenario to understand, remember or function within your environment. For example, if you're in a living room, visualize that room, including the walls, furniture, windows, etc. Describe, point to and/or go to and touch features of the room. It's best to do so in an organized fashion, such as going clockwise or counter clockwise around the room. You might also draw it and put in as many features as possible. It's not important that the drawing

be good from an artistic perspective, but rather that the correct features are noted. You can then go to the various features to locate them and note what they're next to or near. For example, is the front door in the center of a wall or closer to a corner? The light switch is at chest height, but is it to the left or right of the door? Find all the wall outlets, and so on.

Reality visualization also can be helpful in carrying out daily activities. For example, picture the kitchen counter, cutting board, knife and vegetables before you begin to cut them. Whatever the activity or environment, making a mental picture of the situation will help you carry out the task.

People who use reality visualization along with their other senses often feel that their vision has actually improved. What's really happening is that they've gained confidence in their remaining senses, and are using everything they have to their best advantage.

Vision rehabilitation professionals often will include reality visualization as part of their lessons; it's also something you can practice on your own or with family members.

Providing descriptions with as many visual cues as possible, including color, shading and textures can help visual learners create a mental picture of the situation. Auditory learners will find it helpful to incorporate as many sounds as possible in their visualizations; for example, the microwave bell, hum of the refrigerator, etc. And kinesthetic learners may find themselves focusing their visualizations on the activity or using a product.

You can empower yourself by finding out about — and communicating — how you learn best. And vision rehabilitation professionals can help you succeed by being sensitive to your preferred learning style and encouraging the use of sensory cues and visualizations consistent with that style. It's possible to enjoy learning — your way — and continue to do the things you did before, moving into the future with confidence.

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Reader Survey: The Results Are In!

Many thanks to readers who responded to our survey, which appeared in the fall issue. Your feedback is always welcome, at any time. So, if you didn't respond, you still can! We want to continue to ensure that **Sharing Solutions** is relevant to you, our readers.

Overall, you gave **Sharing Solutions** "high marks," including one person who called it a "comprehensive and valuable resource." We're gratified to hear that the newsletter is shared with support group members, clients and students, and that you find our "Coast to Coast" exchange questions helpful in generating lively discussions.

What You Enjoy Most — And Least

Readers find the articles informative and easy to understand, with the vast majority reporting that the newsletter content is "just right." A few people indicated that it's "too simple." While most of you read the newsletter in large print, a number of you listen to it on tape or access it online.

Some of the most popular topics include emotional issues such as overprotection, depression, and relationships, as well as treatment and research. Readers also enjoy articles on managing daily activities through home adaptations and lighting, recreation and leisure activities, tips for dining out, driving and vision, and cane travel. After reading our recent article on using a cane, one person said, "I've had one [a cane] for over a year. I have always kept it folded up because of how others think, but I will now use it."

While the majority couldn't think of topics that they enjoy least, a number of people mentioned that they find articles that don't pertain to their personal situation the "least useful," including one reader who said, "Topics that don't apply to me — I just skip them."

What You'd Like to See in the Future

Numerous topics suggested are, in fact, subjects we've covered in past issues in articles called: "You Can Do It: Enjoying Your Favorite Activities," "What a Cane Can Do for You," "Fix It Yourself," "Overprotection: Support Gone Wrong?" "Diabetes, Vision Loss and You,"

"Depression: It Can Happen to Anyone," "I Can Hear You, But I Can't Make Out the Words!" and "What Can Assistive Technology Do for You?" Contact us for copies.

And there were other recommendations, including topics covered in this issue:

- ✓ Research and treatments of eye diseases (see page 1)
- ✓ Making your home accessible (see page 4)
- ✓ Adult learning styles (see page 5)
- ✓ Exercise and physical fitness
- ✓ Reducing anxiety and stress
- ✓ Handling social situations
- ✓ Maintaining a peer support group
- ✓ Dependence and interdependence
- ✓ Nutrition and vitamins
- ✓ Cross-cultural views on disability
- ✓ Evaluation of low vision devices and adaptive equipment (e.g., CCTVs)

We always welcome your feedback, so if you'd still like to complete the survey, or want a copy of the full report, e-mail sharingsolutions@lighthouse.org or call (212) 821-9470. ●

Order Your Free Copy of "All About Low Vision"

Our updated brochure offers an overview of the most common causes of vision loss, and how low vision and rehabilitation services can help people with uncorrectable vision loss remain safe and independent.

The brochure includes a fold-out poster illustrating how the world looks to someone with macular degeneration, glaucoma and diabetic retinopathy, among other conditions. This poster can be especially helpful in explaining your vision loss to family and friends. To order free copies, call (212) 821-9566 or e-mail kcheng@lighthouse.org. ●

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Lighthouse International is dedicated to helping people of all ages overcome the challenges of vision loss.

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Important Notice Regarding Your Subscription

Sharing Solutions is produced in large print, braille and on audiocassette, and is available for downloading online at www.lighthouse.org/aboutus/newsletters/. Our readers select their preferred format.

While we're happy to provide you with the format that's best for you at no cost, we're sending the current issue in large print only to those who have received it in multiple formats. That's because the cost of providing multiple formats is mounting. The Lighthouse subsidizes these costs, and our goal is to ensure that we continue to reach as many readers as possible.

To receive this newsletter in a different format, please contact us by e-mailing sharingsolutions@lighthouse.org, calling Gina Obando at (212) 821-9485 or writing to Sharing Solutions c/o Lighthouse International, 111 East 59th Street, New York, NY 10022-1202.

Many thanks for your ongoing support! ●