

Sharing Solutions

Spring 2004

A newsletter for
People with Impaired Vision and
Their Support Networks



LIGHTHOUSE
INTERNATIONAL

HOPE WHEN VISION FAILS™

10th Anniversary
Year

Medicare Coverage Leaps Forward

As we mark the tenth anniversary of **Sharing Solutions**, we are excited to share with you the latest breakthrough in obtaining Medicare coverage for vision rehabilitation services. Over time, we have provided updates on the progress of this campaign, and many of you have called or written to your legislators, asking for their support. Here's the latest news.

Congress has recently passed two major bills — the Medicare Prescription Drug Act and the 2004 Appropriations Act — which require that a policy study and a nationwide demonstration of vision rehabilitation services be conducted. Taken together, the two mandates recognize the value of these vital services provided by uniquely trained professionals: orientation and mobility specialists, rehabilitation teachers and low vision therapists.

Under the demonstration project, these professionals will — for the first time — be able to provide services under Medicare in the settings where consumers need them, including in their own homes and other community locations.

continued on page 2

May Is "Healthy Vision Month"

As part of a national public health campaign, the National Eye Institute and the National Eye Health Education Program named May as "Healthy Vision Month." This year's focus — to reduce vision impairment due to diabetic eye disease — emphasizes the importance of regular eye exams to reduce the risk of vision loss. Even if you don't have diabetes, eye exams are critical for early detection and timely treatment of eye disorders, which may not have warning signs or symptoms.

Free Resources

"Healthy Vision Month" materials, including postcards, public service announcements and publications about diabetic eye disease in English and Spanish are available by logging on to www.healthyvision2010.org/hvm or calling (800) 869-2020.

continued on page 2



Medicare ... continued from page 1

The next step, based on the results of the study and the demonstration, will be to make vision rehabilitation services a permanent part of Medicare.

We will continue to keep you informed about the progress of both initiatives. Many, many thanks for your calls and letters to educate members of Congress. They have heard you, and we are now on a firm path toward greatly improved coverage for the critical services that can restore well-being and quality of life for people with vision impairment.

Carol J. Sussman-Skalka

Carol J. Sussman-Skalka
Newsletter Editor



Take Part in the Next Coast to Coast

Have a favorite hobby? Sport? People with vision loss often find new ways to continue long-time interests or take on new pursuits. Discuss the following questions at your next support group meeting or with your family and friends:

- What modifications have you made to continue your favorite leisure activities?
- What techniques, tips or resources have you found helpful?
- Are there hobbies or sports you have had to give up? How come?

Please respond by **July 15, 2004**, to have your responses included in the next issue. Call Carol Sussman-Skalka at **(800) 829-0500**, 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. ●

May Is ... continued from page 1

The FDA Office of Women's Health "Take Time to Care ... about Diabetes" materials are available in English and Spanish by visiting www.fda.gov/womens/taketimetocare/diabetes/default.htm or calling (888) 878-3256 and asking for "Diabetes and Women."

"See for Yourself: Vision and Older Adults," an educational program that includes a video, in English and Spanish, presenter's guidebook and participant booklets, focuses on effective ways to live with vision impairment and promotes the benefits of vision rehabilitation services. Developed by Lighthouse International in collaboration with the National Eye Institute, free copies are available at www.nei.nih.gov/nehep/seeforyourself.htm or by calling (800) 869-2020.

Lighthouse International's "Vision Loss is Not a Normal Part of Aging" poster, booklet and bookmark — along with a companion booklet, "Family and Friends Can Make a Difference" — are online at www.lighthouse.org/vision_loss/index.htm or by calling (800) 829-0500 to receive bulk quantities. Both booklets are also available in Spanish.

Organizations Assisting People Who Cannot Afford Eye Examinations

EyeCare America, a public service foundation of the American Academy of Ophthalmology, provides qualified participants with free eye exams by an ophthalmologist. To learn more, visit www.eyecareamerica.org/eyecare/public or call (800) 222-3937.

Vision USA, a program of the American Optometric Association, provides eligible children and adults with free eye exams by an optometrist. Go to www.aoa.org or call (800) 766-4466.

To receive a copy of "Financial Aid for Eye Care," a Lighthouse fact sheet, call (800) 829-0500 or e-mail info@lighthouse.org. ●

Depression: It Can Happen to Anyone

by Carol J. Sussman-Skalka, CSW, MBA

Feeling down or blue? You may relate to the following: Life seems overwhelming and nothing is going right. Things you used to enjoy hold no interest. You're tired but can't seem to get a good night's sleep. You have no energy, and feel frustrated and unhappy.

Everyone experiences these feelings. Usually, with time, they pass and your mood lifts — maybe you rekindle an old friendship, take up a new hobby or find new meaning in your relationships. Before you know it, you start feeling good about life and what the future holds.

But when is a down period something to be concerned about? A person who feels sad and hopeless day after day, for two weeks or more, may be experiencing clinical depression. Although depression is a serious medical condition that affects about 15% of Americans over age 65, according to the American Association for Geriatric Psychiatry, it is treatable. And the good news is that there is a high success rate for those who get help.

What Causes Depression?

There is no single cause. Depression can be precipitated by an event like a death in the family, a serious illness or the onset of a disability such as vision loss. It also can come about for no apparent reason. Sometimes, changes in brain chemistry can affect mood and trigger depression. People who are caring for family members with chronic medical conditions can become depressed because of the added stress in their lives.

Depression and Vision Loss

Not surprisingly, there is a strong relationship between depression and disability. In fact, older adults with vision impairment are at a greater risk for depression than their fully sighted peers. And, the relationship between vision loss and depression is stronger than the relationship between depression and other age-related conditions like arthritis or hearing loss.

In a research study on depression and vision loss conducted by Lighthouse International, some participants made the following comments: "... very depressing ... frustrating.



Terrible feeling to lose vision, like the end of the world almost." "When the first eye went, I was depressed. But when the second eye went, I fell to pieces."

The Lighthouse study found that people with vision impairment who were depressed were less likely to take advantage of vision rehabilitation services. And these services have been shown to help alleviate feelings of depression. While not everyone who is visually impaired becomes depressed, it's important to become familiar with, and not dismiss or overlook, warning signs.

Signs of Depression

If you or someone you know experiences four or more of the symptoms below (including at least one of the first two) for two weeks or longer, seek a medical professional who can diagnose depression and rule out other health issues. The following list is based on material from the National Institute on Aging and the National Institute of Mental Health:

- an empty feeling or persistent sadness and anxiety
- loss of interest or pleasure in ordinary activities, including sex
- sleep problems (difficulty getting to sleep, waking during the night or early morning, or sleeping too much)
- tiredness, lack of energy
- eating more or less than usual
- difficulty concentrating, remembering or making decisions

continued on page 4

Depression ... continued from page 3

- feeling guilty, helpless, worthless or hopeless
- thoughts of death or suicide
- excessive crying
- being irritable
- recurring aches and pains that don't respond to treatment

Other clues may include a person's withdrawal from friends, family and social activities, as well as noticeable changes in, or neglect of, personal appearance.

Barriers to Getting Help

People who are depressed may be reluctant to get help for a variety of reasons. Some people may not even realize that they're depressed. Others may feel that depression is a sign of weakness and may not want to admit it out of fear or shame. Also a number of people believe that they should be able to solve their own problems; or they may think that nothing can change how they feel because, for example, their vision isn't going to improve. And there are also many misconceptions about what people with vision loss can and cannot do, which may prevent people from seeking help and discovering the possibilities. For example, many are surprised to learn that people with vision impairment maintain their homes, hold jobs, do volunteer work and continue favorite sports and hobbies, such as fishing, playing golf, handicrafts and others.

There's no question that experiencing vision loss is a life-changing experience. People often feel a tremendous sense of loss, which can trigger memories of other losses, further magnifying feelings of sadness, frustration and anger. It's common to have a grief reaction and to mourn the loss of your vision. But for many people, actively seeking professional help is a difficult step to take. It's not easy to admit you need help, and it takes strength to explore new and unfamiliar resources. For example, it may be hard to believe that taking medication or talking about your situation can actually make a difference or improve your life.

What Can Be Done

Depression is treatable. The biggest mistake is not getting help and believing that you have to get used to, and live with, it. Depression is often

managed with a combination of both medication and talk therapy, also referred to as psychotherapy. Approximately 80% of individuals improve with treatment, according to the National Institute of Mental Health.

Many antidepressant medications on the market can be effective in treating depression. While newer drugs have fewer side effects, it's still important to review current medications (prescription and over-the-counter) with your healthcare professional to avoid negative interactions. And there are various types of short-term therapies that can help people better understand their feelings and find new coping strategies. For example, cognitive therapy focuses on identifying and changing negative thoughts that can contribute to depression. Other therapies may focus on interpersonal relationships and/or problem-solving techniques.

There's also the benefit of participating in support groups. Sharing concerns with others in similar situations decreases feelings of isolation, and helps people better understand and cope with their emotions, self-image and practical issues. Further, studies show that exercise programs, good nutrition and a well-balanced diet, in combination with other therapies, also can help people manage symptoms of depression.

Helping a Relative or Friend

Family and friends may feel at a loss as to what to do and how to help when someone close is depressed. They, too, have feelings and may be frustrated or powerless if the person refuses to accept help. Here are some ideas to consider:

- Learn about depression — its signs, causes and treatments — to be in a better position to talk and offer hope.
- Share your concern. Let the person know you care and that there are things that can help him or her through this difficult time.
- Listen without judging. Allow the person to express feelings of anger or resentment about vision loss. Recognize these feelings as real and painful.

continued on page 5

Depression ... continued from page 4

- Review the signs of depression with the individual. This may help him or her to identify with specific behaviors and be more willing to view the situation in a different light.
- Plan an activity, or outing that he or she has enjoyed in the past, or that has made the person feel genuinely useful. Experiencing pleasure may encourage him or her to consider seeking help.
- Discuss the impact on you. Let the person know that you're in this together and that what he or she is going through affects you, too.
- Seek guidance from someone your friend or family member trusts such as other relatives, friends, clergy or a physician.

The Powerful Benefits of Vision Rehabilitation

People new to vision loss often fear the loss of independence, control and privacy. They want to be useful and don't want to be a burden to others. Yet they can feel hopeless about not being able to do the things they did before. As part of a Lighthouse research study on depression, participants shared comments, including: "The day they told me I was blind was the worst day of my life." "The loss of control is giving me anxiety." "There are so many things I want to do and I can't because of the vision. What good am I?"

But the benefits of both counseling and vision rehabilitation services are highlighted by the following comments: "I met people who are blind ... I think it helped me. I never really feel sorry for myself anymore." "They [vision rehabilitation professionals] showed me there was hope for me! They showed me how to use the walking stick." "They gave me this magnifier, which improved my daily life, reading and activities."

Sometimes, a breakthrough comes from discovering a way to continue a favorite activity or task that's especially meaningful to the person. That one accomplishment can make all the difference and may provide the impetus to learn more about other types of modifications, equipment and resources.

So if you or someone you know is dealing with depression and vision loss, realize that there is much that can be done. Most importantly, you don't have to go it alone.

Helpful Resources

The following organizations were sources of information for this article, and offer helpful tips for dealing with depression. Check them out:

National Institute on Aging

www.nia.nih.gov
(800) 222-2225

National Institute of Mental Health

www.nimh.nih.gov
(866) 615-6464

Families for Depression Awareness

www.familyaware.org
(617) 924-9383

National Mental Health Association

www.nmha.org
(800) 969-6642

American Association for Geriatric Psychiatry

www.aagpgpa.org
(301) 654-7850

And to locate a vision rehabilitation agency in your community, call the Lighthouse Information & Resource Service at **(800) 829-0500** or click on "Help Near You" on www.visionconnection.org.

Special thanks to Rosetta Chao, ACSW; Josephine DeFini, PhD; Amy Horowitz, DSW; Anne Kaplin, CSW; and Joann P. Reinhardt, PhD, for their input and review of this article. ●

Carol J. Sussman-Skalka, CSW, MBA,
Director of Special Projects, Lighthouse
International

Coast to Coast: People Share Their Travel Experiences

In our last issue, we asked you to tell us about your travel experiences. Many of you are on the move, visiting family and friends, camping, fishing, sightseeing, going on cruises or to the beach. Whether a trip is for business or pleasure, getting to your destination and enjoying your stay often require extra planning if you have a vision impairment. Here we highlight some helpful resources and share your travel tips.

Getting to Your Destination

However you travel, it's a good idea to inform your travel agent or carrier about the specific help you require. There are many services that can make your trip smoother, so you can relax and enjoy the journey.

● By Air

Special arrangements can be made to ensure your comfort and safety, so check with your airline ahead of time. For example, courtesy vehicles can get you to a gate quickly and safely. Ask to be pre-boarded, and oriented to the plane's facilities and exit locations. If you're traveling with a dog guide, notify the airline for appropriate seating. Airline personnel must assist with making connections, but taking direct flights can avoid the hassle when there are flight delays.

● By Train

To ensure your requests are documented with your reservation record, Amtrak recommends that you speak to a reservation agent rather than book your trip online. If you don't get answers to your questions, ask to speak to a customer service agent. Train personnel can provide assistance in getting to the dining car or rest room, and can help you board or detrain at your destination.

● By Bus

Greyhound offers assistance with boarding and deboarding, luggage, transfers, stowage and retrieval of mobility devices, and destination announcements. Advise personnel of your travel needs in advance.

Plan Ahead

Tourist attractions may have discounts, specific accommodations for people with vision impairment and requirements for advance reservations. For example, museums may offer audio or hands-on tours. Theaters may supply headsets that describe the action on the stage. If you have specific requests, it's usually best to ask ahead of time.

Many people use travel agencies that cater to people with vision loss. Some agencies only offer information, while others provide assistance in travel planning or organize special cruises or sightseeing tours with sighted guides. For a list of these agencies, click on the "Travel" link within the "Community and Lifestyle" section of www.visionconnection.org or call (800) 829-0500 to request our "Tour and Travel Agencies" fact sheet.

While many people travel on their own, others find that it's easier to travel with family, friends or a group. Going on tours leaves the arrangements to others so you can concentrate on socializing and having a good time.

Travel Tips

- Use a white cane. It's one of the most common suggestions from travelers with impaired vision. Even if you don't use the cane as a mobility device, carrying it makes others aware that you are visually impaired and may aid you in getting help when needed. One man emphasized, "My cane goes with me wherever I go. Even if I'm escorted, I still have my cane unfolded."
- Carry a phone card or cell phone with tactile markings. You can store important numbers on your phone, or record them and bring a portable tape recorder, which you can also use to listen to music or books on tape.
- Organize essential items like paper currency, keys, tickets and personal ID using a money belt or hip pack. Also keep handy your

continued on page 7

Coast to Coast ... continued from page 6

itinerary, destination addresses and flight numbers in a format that's accessible to you.

- Separate smaller bills for tips and snacks in a special pocket or wallet. If you're traveling in Europe, the new Euro currency can be distinguished by size, color and tactile characteristics.
- Bring a list of medications, including dosages and an emergency contact.
- Carry a signature guide, and if you use a flashlight, magnifiers or other low vision devices, keep them easily accessible.
- Once in your room, it's important for hotel staff to show you to the nearest fire exit. Even if you're traveling with a companion, you may be alone when an emergency occurs.
- Ask where the TV remote and telephone are, how to adjust heat or air conditioning, how to request a wake-up call or anything else that's important to you.
- Ask hotel staff for help, such as orientation to restaurants, gift shops or fitness centers.
- Be organized when packing. Consider using plastic bags to separate outfits.
- Invest in brightly colored luggage with long handles and wheels. Or use high-contrast tape or ribbons on your baggage to make them easier to identify. A specially designed "luggage locator," which includes a receiver unit (attached to your luggage) and a transmitter for the traveler, can help you retrieve your luggage from baggage carousels.
- When traveling with a dog guide, bring all documentation, such as a health certificate with proof of vaccinations, and notify carriers and hotels in advance. Also bring dog medication, food supplies and water.

While the idea of traveling may appear daunting and scary, one support group member said, "I am planning my first vacation since my sight loss. All these tips have been helpful. I think I can take this adventure without too much stress."

The bottom line: When you travel, be prepared to go with the flow. Don't be surprised if you have to explain to a security screener the purpose of a slate and stylus, for example,

or show hotel staff the proper sighted guide technique. Plan ahead, be organized, ask for and accept needed help, carry a dose of patience and maintain your sense of humor — they all can help make your trip pleasurable and well worth the effort.

Helpful Travel Resources

"New Horizons: Information for the Air Traveler with a Disability" is a free booklet available from the US Department of Transportation's Consumer Information Center, P.O. Box 100, Pueblo, CO 81002; or by visiting www.faa.gov/acr/dat.htm

Call the Toll-Free Hotline for Air Travelers with Disabilities at (800) 778-4838 (voice) or (800) 455-9880 (TTY) daily, between 7 am and 11 pm Eastern Standard Time.

"Access Amtrak: A Guide to Amtrak Services for Travelers with Disabilities" is free and available in limited quantities in large print, braille and on tape. Call (877) 268-7252 or visit www.amtrak.com/plan/accessibility-index.html

For travel resources in Canada, the United Kingdom and Europe, click on the "Travel" link within the "Community and Lifestyle" section of www.visionconnection.org or call (800) 829-0500. ●

Join Our Mailing List!

If you want to receive a free copy of **Sharing Solutions**, available in large print, braille and on audiocassette; or receive an e-mail notification when the newsletter is online, call (800) 829-0500 or e-mail us at info@lighthouse.org.

Sharing Solutions

Cynthia Stuen, DSW
Senior Vice President for Education

Carol J. Sussman-Skalka, CSW, MBA
Newsletter Editor

Sarah Lloyd
Director of Educational Publications

Laurie Silbersweig
Director of Editorial Services

Jaine M. Schmidt
Creative Director

Photos by Robert A. Lisak and Jayne DiGregorio

This newsletter is available in alternate formats and on our Web site: www.lighthouse.org. To add your name to our mailing list, call (800) 829-0500 or e-mail us at: info@lighthouse.org.

Lighthouse International

Barbara Silverstone, DSW
President and CEO

Lighthouse International is a leading resource worldwide on vision impairment and vision rehabilitation. Through its pioneering work in vision rehabilitation services, education, research, prevention and advocacy, Lighthouse International enables people of all ages who are blind or partially sighted to lead independent and productive lives. Founded in 1905 and headquartered in New York, Lighthouse International is a not-for-profit organization, and depends on the support and generosity of individuals, foundations and corporations.

Lighthouse International
111 East 59th Street
New York, NY 10022-1202
Tel: (212) 821-9200
(800) 829-0500
Fax: (212) 821-9705
TTY: (212) 821-9713
www.lighthouse.org

© 2004 Lighthouse International

5 Printed on recycled paper

P380-S04/10m/4-04



LIGHTHOUSE INTERNATIONAL

111 East 59th Street
New York, NY 10022-1202

ADDRESS SERVICE REQUESTED

10th Anniversary Year

We are especially grateful to the **Wallerstein Foundation for Geriatric Life Improvement** for their very generous support of the **tenth anniversary** issues of **Sharing Solutions**, a worldwide newsletter that enables people with vision impairment, and their family and friends, to access and share vital information.

And many thanks to **Rosalind Scheer**, a Lighthouse volunteer, who has recorded **Sharing Solutions** for the last ten years.

Thanks for Sharing ...

Nikki Arterburn, Program for Visually Impaired Adults Support Group, IN; **Elinor Waters, MD**; **Betty Cain**, Low Vision Support Group MAX II, SC; **Mary Rumman**, Turner Geriatric Clinic Low Vision Support Group, MI; **Kate Chamberlin**, The Lemonade Society, NY; **Paul Wohlfeil, IL**; **Florence Woodworth**, Friendship Village Low Vision Support Group, AZ; **Margaret Hunerjager, MI**; **Linda Scribner**, League for the Blind and Disabled Support Groups in Auburn, Decatur and Fort Wayne, IN; **Juleen Farnstrom**, South Central VIPS, NE; **Gary Ozinga, MI**

To get in touch with people who shared their experiences, call the Lighthouse toll free at (800) 829-0500 or e-mail info@lighthouse.org.