

Sharing Solutions

Fall 2004

A newsletter for
People with Impaired Vision and
Their Support Networks



LIGHTHOUSE
INTERNATIONAL

HOPE WHEN VISION FAILS™

Thanks for Your Input!

We listen. In every **Sharing Solutions**, we ask for feedback on issues that matter to you. We're interested in your thoughts and experiences — your frustrations and concerns, as well as your successes and solutions for making daily life easier when vision is a problem. You tell us your personal stories, triumphs, tips and advice for living better with vision loss. And in turn, we share your responses in our "Coast to Coast" column for the benefit of all our readers.

In this issue, we feature your suggestions for continuing to enjoy favorite leisure activities. In addition, we invite you to participate in our next "Coast to Coast" exchange on the subject of driving. The decision to drive — or not to drive — is a critical one for so many people with vision loss. And we look forward to sharing your feedback about this complex issue.

And we keep listening. In response to your requests, we have included an article about Charles Bonnet Syndrome. This common side effect of vision impairment causes people to see things that they know aren't really there. If you share this experience, there is nothing wrong with your mind. Read on to learn about this often-misunderstood condition.

Thanks for making **Sharing Solutions** a relevant resource for everyone. Enjoy the newsletter!

Carol J. Sussman-Skalka

Carol J. Sussman-Skalka
Newsletter Editor



You Can Do It!

Whatever your game, whatever your hobby, or whatever you do for fun or relaxation, don't assume it can't be done because of a vision problem. In our last issue, we asked you to share tips for continuing to enjoy favorite activities. Here's what you had to say, along with some additional suggestions and resources for staying active.

Sports

- **Bicycle Riding:** It takes two! Ride a tandem bicycle with a sighted friend who steers while both of you pedal. Ask your partner to tell you about upcoming hills, turns or the need to brake along the way, and to describe the changing scenery. If you prefer, ride a stationary bicycle to get the same aerobic benefits.
- **Bowling:** A guide rail is the key: Slide one hand along its smooth surface while delivering the ball with the other. Or ask a sighted friend to position you. Your friend can also call out the numbered locations of the pins left standing.
- **Fishing:** You can't go wrong with pre-rigged lines — the hook and sinker are already threaded and clip to the end of your fishing line. Or use floss or wire-needle threaders to thread line through the lure, hook or sinker. Fluorescent-colored fishing line may be easier to see if you're partially sighted. And organizing your tackle box using containers with tactile or large-print labels can help you find what you're

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looking for quickly. Here's an important safety tip: place hooks in corks to prevent sticking yourself accidentally.

- **Golf:** Get a feel for the course: On the green, walk from the ball to the flag and back to get a sense of the distance, slope and break. Some golfers find it helpful for a partner to stand next to the hole to provide a larger target and/or to make a sound. Inquire about the availability of an audio guide of the golf course. Or ask partners to tell you about bunkers, flags, direction and distance. The rules allow players with vision loss to ground the club in a bunker without a penalty. Fluorescent-colored balls may be easier to see, and painting the heads of clubs white will help them contrast well with the grass.
- **Yoga:** Instructors are often accommodating to people with vision loss by wearing contrasting clothing to enhance visibility, providing hands-on assistance to execute a particular move or position, and allowing you to follow their moves with your hands.
- **Swimming:** A pool with roped lanes can help with orientation. And when you're swimming laps, count how many strokes it takes to swim the length of a pool so you can know when to slow down as you near the end.
- **Snow Sports:** "Snow skiing is exhilarating and fun!" exclaims one enthusiast. Take advantage of sighted guides for both downhill and cross-country skiing. A ski guide chooses the line to be taken during the descent, describes slope conditions and terrain changes, and indicates timing and direction of turns. Special commands are used for cross-country skiing to ensure communication about bumps, dips, hills and turns.

Bring a buddy: Go snowshoeing with a friend. One woman describes how: "My husband (or friend) walks in front holding a long stick and I hold the other end. It's great exercise and a fun walk."



Activities Around the House

- **Gardening:** There are as many tips as there are plants! You can grow plants with distinguishable scents (lavender and geraniums, for example) or different textures (African violets and amaryllis). Use large-print tags or place plants into containers of different sizes or shapes to make them easier to identify. Paint or tape the handles of garden tools to make them easier to see. White paint on the tines of a hoe provides excellent contrast with the soil.

If you want to plant a garden, use a cane as a guide for planting a straight row, or lay down two fishing lines and plant seeds between them. Place mulch or landscaping felt between plants and seedlings to reduce the need for weeding. Use contrast to help with orientation: place a brightly colored strip down the center of a pathway, or use

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something textured like gravel or bark. And a radio playing on your porch makes it easier to find your way back.

- **Handicrafts:** Think twice before you give up knitting, crocheting and sewing. Getting organized is key: Separate thread and yarn by color using large-print or braille labels; separate skeins using plastic Ziploc® bags or empty coffee cans with plastic lids. Create a one-inch hole in the center of the lid and thread the yarn through to prevent tangles.

Use tape measures or rulers with tactile or large-print markings. And there are talking tape measures and those that fold at one-inch intervals. Invest in needle-threading devices, such as wire-loop threaders, chimney-style threaders, spread-eye needles or self-threading needles (also available for sewing machines), or try needles with larger eyes.



Enlarge patterns or instructions on a copier machine or ask someone to record instructions on a cassette. And finally, experiment with flexible lighting, such as gooseneck, swing-arm or adjustable lamps, which can be positioned to focus light on your task. Lamps with built-in magnifiers or magnifier attachments are also helpful.

- **Knitting and Crocheting:** Large knitting needles or crochet hooks make it easier to feel the stitches. If you're partially sighted, contrasting yarn color can further enhance visibility. To avoid having to change yarn frequently, use multi-colored yarn. A small abacus can help you keep count of rows and stitches. Or place a button or coin in a container as each row is completed.

As you work, keep your fingers very close to the needle points so you can feel the stitches come off. If you've dropped a stitch and can't find it by touch, lay the piece on a contrasting surface to try to locate it. Mark the stitch with a safety pin. If the stitch is loose or large, try to pick it up with your fingers or a crochet hook and thread it back. If the dropped stitch is not far from where you stopped, it's easier to undo stitches back to that point and then continue working from there.

- **Sewing:** Outline sewing patterns with bold-tip pens, tactile markings, such as Hi-Marks, or colored tape to help you see or feel the cutting line. To make frequently used patterns permanent, transfer them onto heavy cloth or cardboard that is edged with contrasting seam binding or tape. The edge is a different texture from the fabric and protects the pattern from being cut.

Pull thread across beeswax to prevent it from knotting or curling. A good rule of thumb is to use strands about arm's length. Use safety pins instead of straight pins; consider iron-on hemming tape instead of sewing a hem. Mark the settings of your sewing machine with raised dots and place a strip of contrasting or textured tape on the bed of the machine as a guide for sewing your preferred seam width.

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For readers who enjoy quilting, use fabrics with varied textures or contrasting colors.

- **Board Games and Cards:** Many games — Scrabble,[®] Rummikub[®] and playing cards — are available in large print and/or braille. Ask your partners to call out the cards as they are being played. If you prefer chess or checkers, some sets are adapted so that one board color is raised or textured, and each set of pieces has a different-shaped top (flat or pointed).
- **Playing Musical Instruments:** Readers continue to play music by ear or memory, or with the help of enlarged musical scores. Others take up new instruments with the help of instructional audiotapes.
- **Reading:** In addition to enjoying large-print books, or using a magnifier or CCTV to read, people use talking books and books in braille. They are available free of charge from The National Library Service at **(800) 424-8567**. Periodicals and newspapers are broadcast over special radio channels operated by Radio Reading Services. To locate one near you, call **(800) 829-0500**. And NFB-NEWSLINE[®] provides free telephone access to a wide range of national and local newspapers; call **(410) 659-9314** for information.

These are just some of the hobbies and activities people who are blind or partially sighted continue to enjoy. The list goes on and on to include water aerobics, water skiing, working out on exercise machines, talking on ham radio, carpentry, crafts, painting furniture, walking, hiking and so much more. A reader who is an avid — and safe — woodworker holds up his hands and exclaims, “I still have ten!”

However, some people report giving up activities like ping pong, tennis, fine embroidery, photography and painting. And not being able to drive has affected one reader’s ability to keep up ballroom dancing.

Give It a Shot!

Discuss your favorite pastime with a low vision specialist or other vision rehabilitation professional to see what adaptations are possible for your vision problem, including the use of magnifiers and a CCTV. Learning new ways to continue a life-long interest may take time and patience, but may be well worth the effort. “Always try and give it a shot. You may surprise yourself,” advises one of our readers.

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“I See Purple Flowers Everywhere: The Many Visions of Charles Bonnet Syndrome”

by Lylas G. Mogk, MD, and Marja Mogk, PhD; with Carol J. Sussman-Skalka, CSW, MBA

Do you ever see things you know are not there but look real anyway? It’s a common side effect among people with vision impairment. While we refer to it as “phantom vision,” the technical term is “Charles Bonnet Syndrome.” If you’ve experienced this, rest easy. Your mind is fine. It’s your eyes that are playing tricks on you.

What Exactly Is Charles Bonnet Syndrome?

Charles Bonnet, an 18th century Swiss naturalist and philosopher, is credited as the first person to describe the syndrome. Like his grandfather, who had low vision and saw men, women, birds and buildings he knew were not there, Charles experienced similar phantom visions when his own vision deteriorated.

One explanation compares this condition to phantom limb experiences. People who have a limb amputated may still feel their toes or fingers, or may experience itching on an arm that is not there. This happens because the limb’s nerves are still active and sending signals to the brain, which the brain interprets as sensations from the missing limb. Similarly, when retinal cells become impaired and are no longer able to receive and relay visual images to the brain, the visual system begins firing off images on its own.

Often, these images are not related at all to a person’s life. Sam, who has macular degeneration, said, “I see little monkeys with red hats and blue coats playing in the front yard.” Sam had no doubt that the monkeys he saw were not real ones. As a result, he wasn’t concerned about his mind. However, he was worried about what others would think, so he kept it to himself.

Is the Syndrome Common?

Studies show that Charles Bonnet Syndrome affects between 10 and 40 percent of people with low vision. Our research suggests that

... when retinal cells become impaired and are no longer able to receive and relay visual images to the brain, the visual system begins firing off images on its own.

it is more likely to appear if you have visual acuity between 20/120 and 20/400. If your vision falls within these parameters, your eyes still have a great deal of power, even though they aren’t receiving or sending as many images as previously. As a result, your eyes may be providing additional images of their own.

We can’t predict whether you will see images and, if you do, how frequently they will occur or how long they will last. You may never experience Charles Bonnet Syndrome, you may have it for only a few months, or you may have it for years. You may see images everyday, a few times a week or several times a month.

Are You Sure This Is Not a Psychiatric Problem?

Yes! Charles Bonnet Syndrome is no more than a side effect of vision loss. The six criteria for Charles Bonnet Syndrome (outlined by Naville in 1873 — and still applicable today) can help you determine whether or not you are experiencing phantom vision. Ask yourself whether the images you see have the following six characteristics:

“1. They occur when you are fully conscious and wide awake, often during broad daylight.

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2. They do not deceive you; you are aware that they are not real.
3. They occur in combination with normal perception. For example, you may see a sidewalk clearly but find it covered with dots, flowers, or faces.
4. They are exclusively visual and do not appear in combination with any sounds or bizarre sensations.
5. They appear and disappear without obvious cause.
6. They are amusing or annoying but not grotesque.

“Since ophthalmology has paid so little attention to Charles Bonnet Syndrome, many doctors don’t realize how common it really is, and some may not be familiar with it at all.”

What Do People Actually See?

Patients “have reported seeing cartoon characters, flowers in the bathroom sink, hands rubbing each other, waterfalls and mountains, tigers, maple trees in vibrant autumn foliage, yellow polka dots, row houses, a dinner party and brightly colored balloons. Many people see faces or life-size figures that they’ve never seen before. One of the most remarkable qualities of these figures is that they almost always wear pleasant expressions and often make eye contact with the viewer. Menacing behavior, grotesque shapes and scenes of violent conflict are not, to my knowledge, a part of the syndrome.

“Usually the same image or set of images reappears to each person, sometimes in the same places or at the same time of day. Sam’s monkeys usually materialized around sunset, cavorting across the lawn or around the big blue easy chair by the fireplace. They stayed for ten or 20 minutes several times a week for two years and then began to appear less frequently. ... Sometimes the images are exactly to scale and sometimes larger or smaller than life. ... Joe’s horses looked like children’s toys at a distance of ten feet, but as they galloped outside they became Clydesdales and then stallions worthy of Gulliver.”

Rosa saw “flowering trees” with large, beautiful pink flowers. She knew that they weren’t real because it was autumn. But when she told a friend what she was seeing, her friend was not convinced with Rosa’s explanation. Rosa stopped telling people about her visions. She acknowledged, “You have to be careful what you say.”

“Sometimes Charles Bonnet Syndrome images can become confused with dream images. For example, several of my patients have reported frightening moments when they thought they saw a man standing in their bedroom or hallway. These men, however, were often dark-clad or indistinct figures that appeared as the patient was relaxing on a couch, dozing or in bed waiting to fall asleep, or just awaking. These figures were probably residual dream images. ... They are not typical of Charles Bonnet Syndrome.”

Is Charles Bonnet Syndrome Treatable?

A majority of people do not find their phantom vision disturbing, probably because the images they see are amusing, pleasing or entertaining. You may want to discuss your phantom vision with your doctor, particularly if you feel bothered or distressed by your experiences. While there does not seem to be any specific medications that work for everyone, many people find that learning more about the condition helps to reassure them.

Buddy’s “purple flowers” appeared in his bathroom and on his clothing. He got a chuckle when he imagined what golf pants with purple flowers would look like to other people. He had a cousin with macular degeneration who saw frogs in his bathtub and a very attractive woman stationed on his back porch. Buddy’s purple flowers didn’t compare to the woman on Harry’s porch; and Harry, though disappointed that his “vision” was not real, found that he enjoyed it quite a lot! ●

This article is based on, and includes quotes from, a chapter in **Macular Degeneration: The Complete Guide to Saving and Maximizing Your Sight**, written by Lylas G. Mogk, MD, and Marja Mogk, PhD, published by The Ballantine Publishing Group (2003).

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And don't forget that you can team up with a "buddy" for help. If you attend a support group, ask around to find others who share your interests. If you have Internet access, log onto www.visionconnection.org, and visit the "Community & Lifestyle" and "Recreation & Leisure" sections for additional information and resources. Or call the Lighthouse Information & Resource Service toll free at **(800) 829-0500** for free recreation and reading options fact sheets.

Information for this article was also obtained from the US Association of Blind Athletes, US Blind Golf Association, SportsVision, The Royal National Institute of the Blind, Vision Australia Foundation, Royal Blind Society, Blind Sport New Zealand, Ski for Light Canada and Lighthouse International's publication, **Take Charge of Your Life with Vision Rehabilitation.** ●

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Thanks for sharing ...

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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.

Take Part in the Next "Coast to Coast" on Driving and Vision Loss

One of the most devastating consequences for people who become visually impaired is the loss of the ability to drive. The decision to stop driving is not easy. In fact, a Lighthouse research study suggests a significant number of older adults with vision impairment continue to drive, although many also change where and when they drive. Driving is a means to accomplish daily tasks and to maintain an active social life. It is also linked to feelings of independence and self-worth. The transition from driving to "giving up the keys" can be emotionally trying and have a significant effect on one's life.

The Lighthouse Arlene R. Gordon Research Institute has initiated a five-year study funded by the National Institute on Aging to better

understand driving transitions among people with vision loss. The study will follow current drivers who are visually impaired for a two-year period and identify what influences them to change their driving behavior or to stop driving, and the psychological impact of these decisions.

Insights about what can make driving transitions less distressing can assist professionals, family members and friends to help older adults make timely decisions about driving.

We're interested in hearing from drivers and ex-drivers alike. Let the following questions be your guide. Discuss them at your next

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Sharing Solutions

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Lighthouse International

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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.

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support group meeting or just tell us about your own situation.

For people who still drive:

- What considerations would lead you to discontinue driving?
- What practical and emotional consequences do you anticipate?

For people who have stopped driving:

- What were the most important influences on your decision to stop driving?
- What practical and emotional consequences did you face, and how have they changed over time?

- What has helped in your adjustment since you stopped driving? What has made it difficult?

Please respond by **January 15, 2005**, so that we can include your responses in the next issue. Call Carol Sussman-Skalka toll free at **(800) 829-0500**, or e-mail her at sharingsolutions@lighthouse.org. You also can send letters or tapes to Carol at Lighthouse International, 111 East 59th Street, New York, NY, 10022-1202. ●