

## **Patient Handout**

An American Academy of Ophthalmology Initiative in Vision Rehabilitation

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# Making the Most of Remaining Vision

If you are having difficulty with things such as reading, using your cell phone or computer, or managing glare,  $SmartSight^{TM}$  can help, with tips about lighting, contrast, magnification and vision rehabilitation. There are many new technologies that are of great assistance to people with low vision. Cell phone cameras can magnify, and smartphone applications can help you identify objects and colors or read barcodes. Losing vision does not mean giving up your activities, but it may mean learning new ways to do them.

# Patterns of Vision and Vision Loss

**Central Vision** is the detailed vision we have when looking directly at an object. Macular Degeneration (MD) affects central vision. Diabetic retinopathy can affect central and peripheral vision.

**Peripheral Vision** is the less detailed vision we have for everything we are not looking directly at. Glaucoma and Retinitis Pigmentosa affect peripheral vision first. Strokes can affect one side of peripheral vision. Diabetic retinopathy can affect central or peripheral vision.

**Monocular Vision** is when one eye has much less vision than in the other eye. This can impair fine depth perception.

# The Experience of Vision Loss

It is important to acknowledge the anger and frustration you may feel upon learning that your vision loss is irreversible. Getting the help you need to work through these feelings and become aware of the strategies of vision rehabilitation will help keep you active and avoid depression. You can live well with low vision, but you cannot live well with depression. Counseling and a good support group can help you recognize that your value to yourself and others does not depend on your vision and that you are worth the effort it takes to learn to make the most of the vision you have.

# The Phantom Vision of Charles Bonnet Syndrome (CBS)

About 20 to 30 percent of those with vision loss see repeated life-like images that they know are not real. This is called Charles Bonnet Syndrome and it is not a loss of mental capacity; it is just a part of vision loss, for some.

# Make the Most of Remaining Vision

## Using Your "Next-Best Spot": Scotomas and PRLs

When the center of your vision is obscured by a blind spot (scotoma), you can use the "next-best spot" (the Preferred Retinal Locus, or "PRL"). Adapting to using noncentral vision can be challenging. Vision rehabilitation can assist you to use your remaining vision optimally.

## Make Things Brighter

**Improve lighting:** Use a gooseneck lamp and carry a pocket flashlight.

**Reduce Glare:** Indoors cover shiny counters. Try yellow, amber, yellow or plum tinted glasses or clip-ons. Visors are useful indoors or outdoors.

**Increase contrast:** Use a black rollerball or felt pen, not a ballpoint. Draw a dark line where you need to sign, use a white cup for coffee.

# Make Things Bigger

Move closer: Sit close to the TV and up front at performances.

**Enlarge:** Get large print checks, playing cards, bingo cards, crosswords, calendars and books and large phone dial, TV remotes, and keyboards.

**Magnify:** Get an e-reader or electronic tablet for books. Use a lighted handheld magnifier for price tags and menus, a stand magnifier or video magnifier for reading text, or magnification on your computer.

Organize: Designate a spot for everything. Minimize clutter.

**Label:** Mark thermostats and dials with tactile marking paint from the fabric store. Label medications with markers or rubber bands. Safety- pin the labels of similar-colored clothing.

# Substitute: Let's Hear it For Ears

Get books and magazines in audio format. Get a talking watch, calculator, glucometer or use audio screen readers to listen to your computer or cell phone texts. (See Resources)

# **Participate**

Don't isolate yourself. Keep your social group, volunteer job, golf or bowling. You might need large print, a magnifier, a ride or someone to spot your ball, so ask for the help you need. Staying home to avoid asking for help is not independence. Friends are honored to be asked.

# Driving and Alternative Transportation

Pick your times and routes carefully. Use a GPS. If driving is difficult, cars appear unexpectedly, drivers honk at you or you are having fender- benders, consider alternatives. Sell your car and with the money you are saving by not paying car insurance take a taxi, buy gas for a friend who drives or hire a part-time driver. Try a 3-wheel bike or electric scooter. Walk when you can.

# For Family and Friends

To keep up their spirits, your loved one needs to be empowered to do as much as possible independently. Recognize the challenge of vision loss and offer help, but don't take over their tasks. Instead help them make the adaptations necessary to accomplish them on their own.

# Resources

#### More Information About Low Vision in Children

- o American Academy of Pediatric Ophthalmology and Strabismus
  - Resources for low vision and cerebral/cortical visual impairment <u>https://aapos.org/education/educational-resources/pediatric-low-vision-education</u>
  - More information about childhood eye conditions. https://aapos.org/patients/eye-terms
- Lions Club: Videos and webcasts about low vision conditions and rehabilitation http://kanlovkids.kssdb.org/training

# Audio books and magazines are available by mail or by downloading to a device

- o National Library Service for the Blind and Physically Handicapped (NLS) 888-657-7323. Books and player provided free <a href="http://www.loc.gov/nls/">http://www.loc.gov/nls/</a>
- o Bookshare accessible online library: \$50 annually; free for students Read on your computer, tablet, smart phone or assistive device. <a href="http://www.bookshare.org/">http://www.bookshare.org/</a>
- Choice Magazine Listening (quarterly issues of recorded magazine selections, unabridged) 888-724-6423 <a href="http://www.choicemagazinelistening.org/">http://www.choicemagazinelistening.org/</a>
- Audio Bibles for the Blind https://www.auroraministries.org/pages/audio-bibles
- NFB-NEWSLINE \* https://www.nfb.org/programs-services/nfb-newsline

# Large Print Materials and Visual Devices

- o American Printing House for the Bind https://www.aph.org/shop/
- Learning Sight & Sound (LS&S) https://www.lssproducts.com/ 800-468-4789
- o MaxiAids http://www.maxiaids.com/ 800-522-6294
- Independent Living Aids <a href="http://www.independentliving.com/">http://www.independentliving.com/</a> 800-537-2118
- New York Times Large Print Weekly
   https://homedelivery.nytimes.com/HDS/LargeTypeWeeklyHome.do?mode=ChooseCountry.LargeTypeWeekly 800-631-2580

# Technologies: Computers, Cell phones, Video magnifiers

- Search "voice to text software"
- Apple and Mac devices
  - Apple accessibility information <a href="http://www.apple.com/accessibility">http://www.apple.com/accessibility</a> 877-204-3930
  - AppleVis user community <a href="http://www.applevis.com/">http://www.applevis.com/</a>
- Facebook accessibility
  - o Help page <a href="https://www.facebook.com/help/accessibility">https://www.facebook.com/help/accessibility</a>
  - Facebook page <a href="https://www.facebook.com/accessibility">https://www.facebook.com/accessibility</a>
- o Microsoft accessibility tutorials
  - http://www.microsoft.com/enable/default.aspx 800-936-5900
- Accessible cellphones <a href="http://www.accessiblephones.com/">http://www.accessiblephones.com/</a>
- o Computers for the Blind (CFTB) <a href="http://www.computersfortheblind.net/">http://www.computersfortheblind.net/</a>
- ZoomText magnification computer software <a href="https://www.zoomtext.com/">https://www.zoomtext.com/</a> 800-444-4443
- Video magnifiers: List of products and descriptions
   https://www.afb.org/blindness-and-low-vision/using-technology/assistive-technology-products/video-magnifiers

# National Organizations for Support, Information and Research Updates

- o American Diabetes Association http://www.diabetes.org/800-342-2383
- o American Printing House for the Blind: <a href="https://www.aph.org/800-223-1839">www.aph.org/800-223-1839</a>
- o American Foundation for the Blind: http://www.afb.org/ 212-502-7633
- American Macular Degeneration Foundation <a href="http://www.macular.org/">http://www.macular.org/</a> 888-622-8527
- Association for Macular Diseases/Ophthalmic Edge <u>https://ophthalmicedge.org/patient/about-us/</u>
- o Clinical trials, search a database of privately and publicly funded clinical studies conducted around the world http://clinicaltrials.gov/
- o Glaucoma Research Foundation <a href="http://www.glaucoma.org/">http://www.glaucoma.org/</a> 800-826-6693
- o Hadley School for the Blind online courses <a href="http://www.hadley.edu/">http://www.hadley.edu/</a> 800-323-4238
- Macular Degeneration Foundation http://www.eyesight.org/888-633-3937
- o Macular Degeneration Partnership http://www.amd.org/888-430-9898
- o Macular Degeneration Association, <a href="https://macularhope.org/">https://macularhope.org/</a> 855-962-2852
- o MD Support group list <a href="http://www.mdsupport.org/">http://www.mdsupport.org/</a> (816) 588-7747
- o National Eye Health Education Program, <a href="http://www.nei.nih.gov/nehep">http://www.nei.nih.gov/nehep</a> English and Spanish
- National Federation of the Blind: https://www.nfb.org/410-659-9314 (toll call)
- National Industries for the Blind: <a href="https://www.nib.org/about/">https://www.nib.org/about/</a> 703-310-0500 (toll call)
- o National Institutes of Health database of privately and publicly funded clinical trials around the world <a href="https://clinicaltrials.gov/">https://clinicaltrials.gov/</a>
- o Vision Aware<sup>™</sup> http://www.visionaware.org/
- o In Canada
  - Vision Loss Rehabilitation Canada <a href="https://www.visionlossrehab.ca/">https://www.visionlossrehab.ca/</a> 1-844-887-8572
  - CNIB Foundation <a href="https://cnib.ca/en/sight-loss-info?region=bc">https://cnib.ca/en/sight-loss-info?region=bc</a> 1-800-265-4127

# Vision Rehabilitation Self-Help Materials

- VisionAwareTM Emotional Adjustment to Vision Loss
   https://www.visionaware.org/info/emotional-support/1

   Printing House for the Blind
- Fall prevention brochure\_Centers for Disease Control and Prevention (CDC): <u>http://www.cdc.gov/HomeandRecreationalSafety/Falls/index.html</u>
- o A Self-Help Guide to Nonvisual Skills (PDF), D. Roberts, 2011http://www.mdsupport.org/guide.pdf
- Making Life More Livable: Simple Adaptations for Living at Home After Vision Loss,
   M. Duffy, American Printing House for the Blind 800-223-1839
   <a href="https://www.aph.org/product/making-life-more-livable-simple-adaptations-for-living-at-home-after-vision-loss/">https://www.aph.org/product/making-life-more-livable-simple-adaptations-for-living-at-home-after-vision-loss/</a>
- Macular Degeneration: The Complete Guide to Saving and Maximizing Your Sight, L. Mogk, MD, & M. Mogk, PhD, NY: Ballantine Books 2003
- o *The First Year Age-Related Macular Degeneration*, D. Roberts, NY: Da Capo Press, 2006
- Overcoming Macular Degeneration: A Guide to Seeing Beyond the Clouds, Y.
   Solomon, MD, & J. Solomon, NY: BookSurge Publishing 2009

#### Pediatric and Youth Resources

- FamilyConnect http://www.familyconnect.org/
- CVIScotland: for children with cerebral/cortical visual impairment and their families <a href="https://cviscotland.org/">https://cviscotland.org/</a>
- o Lighthouse Guild Support for Parents <a href="https://www.lighthouseguild.org/patients-families/tele-support-services/support-for-parents/">https://www.lighthouseguild.org/patients-families/tele-support-services/support-for-parents/</a> 800-562-6265
- o Perkins School for the Blind https://www.perkins.org/
- o Texas School for the Blind https://www.tsbvi.edu/

# Camps and Organizations

- Space Camp for Interested Visually Impaired Students <a href="http://www.scivis.org/index.htm">http://www.scivis.org/index.htm</a>
- o U.S. Assoc. of Blind Athletes http://www.usaba.org/

## Locate Vision Rehabilitation Services Near You

◆ VisionAware<sup>™</sup> https://visionaware.org/

Ask if services include: A vision rehabilitation consultation by an MD or OD; device recommendations; devices for loan; rehabilitation training for reading, writing, shopping, cooking, lighting, glare control; home assessment; mobility training; support groups. Ask about cost: free, billed to insurance, other? Medicare covers most services; not devices.

#### Veterans

Can receive services and devices free of charge.

U.S. Department of Veterans Affairs <a href="https://www.rehab.va.gov/blindrehab/">https://www.rehab.va.gov/blindrehab/</a> 844-698-2311