Living with Vision Loss

Vision Loss Resources
## TABLE OF CONTENTS

- Introduction ................................................................. 1
- Background Information and Terminology .............. 2
- Leading Causes of Vision Loss ................................. 4
- Optical Low Vision Aids .................................................. 9
- Non-Optical Low Vision Aids ........................................ 11
- Emotional Aspects of Vision Loss ............................. 11
- Meeting Someone With Vision Loss ...................... 15
- Tips for Making a Home Accessible ......................... 19
- Resources ........................................................................... 22
- Conclusion ......................................................................... 24
INTRODUCTION

The experience of vision loss can have major implications for people coping with it as well as for their family, friends or care providers. This publication is a collaborative effort by staff and volunteers at Vision Loss Resources. It is designed to provide background information about vision loss and some practical suggestions for enhancing the lives of all people affected by blindness or visual impairment.

This booklet, Living with Vision Loss, is also available in Spanish and as an audiobook in English and Spanish. A printed version is available at our offices.

VISION LOSS RESOURCES

West Metro Office          East Metro Office
1936 Lyndale Avenue S.     216 S. Wabasha Street
Minneapolis, MN 55403     St. Paul, MN 55107
612-871-2222 (V/TTY)       651-224-7662

Website:  www.visionlossresources.org
E-mail: info@vlrw.org
BACKGROUND INFORMATION

Visual impairment is a vision loss that impacts daily activities. It is fairly common in the general population affecting one person in twenty. Visual impairment is considered severe when a person is no longer able to read newspaper print with the strongest standard corrective lens.

As a person ages, the likelihood of vision loss increases significantly. Over the age of 65, one in six people experiences serious vision loss. This rate increases to one in four for those over 85.

Some basic information helps in understanding vision loss. It is important to remember that any two people, even with the same visual condition, may be affected differently and that an individual’s vision may fluctuate from day to day.

TERMINOLOGY

Legal Blindness

The definition of legal blindness is central visual acuity of 20/200 or less in the better eye with the best correction. This means the ability to identify at 20 feet or less with the best correction what those without visual impairment can identify at 200 feet. Legal blindness can also mean a severely restricted field of vision. For example, a person whose peripheral field of vision is restricted to a diameter of 20 degrees or less is considered legally blind even though central visual acuity is better than 20/200.
Legal blindness does not necessarily mean total loss of sight. In fact, over 90% of people who are legally blind have some residual vision; this remaining vision can often be quite useful.

**Low Vision**

Low vision is defined as decreased visual acuity of 20/70 or less with the best correction. Low vision can result from birth defects, disease, injuries and conditions related to the aging eye. Reduced central or reading vision is the most common symptom. Low vision may also cause decreased peripheral vision, reduced or lost color definition or the inability to adjust to light, contrast and glare. People with low vision have useful remaining sight that is often improved with low vision devices.

**Low-Vision Aids**

Any mechanism that enhances remaining vision is considered a low-vision aid. Different aids may be needed for different purposes and all should be tested before purchase to determine effectiveness. Professional advice in finding and learning to properly use low vision aids is available from low-vision specialists and agencies serving people with vision loss.
LEADING CAUSES OF VISION LOSS

Cataracts

When the lens -- the part of the eye located directly behind the pupil-- changes from clear to opaque, a cataract has developed. This clouding usually occurs first in the central vision and then extends outward to the periphery. Blurry vision, double images or intolerance to bright sunlight may all be signs of developing cataracts.

Cataracts associated with aging are the most common. However, there are congenital cataracts from birth, secondary cataracts due to disease and traumatic cataracts following injury to the eye.

Surgery is the sole treatment, and this simple procedure usually is successful. The eye’s natural lens is replaced with a lens implant, contact lens or glasses.

Sometimes a cataract should be removed even if it does not cause problems with your vision. For example, a cataract should be removed if it prevents examination or treatment of another eye problem, such as age-related macular degeneration or diabetic retinopathy. If your eye care professional finds a cataract, you may not need cataract surgery for several years. In fact, you might never need cataract surgery. By having your vision tested regularly, you and your eye care professional can discuss if and when you might need treatment.
If you choose surgery, your eye care professional may refer you to a specialist to remove the cataract. (NEI/NIH, 2013)

**Diabetic Retinopathy**

One of the possible complications of diabetes is diabetic retinopathy. Vision loss is caused by blood vessels in the retina-- the paper-thin tissue that lines the back of the eye-- rupture and bleed into the fluid of the eye. This causes blurred vision and may also have a reddish tint. As the tiny ruptures heal, scars form and damage the retina.

Treatment with laser surgery is available. However, new hemorrhages may occur.

During the first three stages of diabetic retinopathy, no treatment is needed, unless you have macular edema.

Proliferative retinopathy is treated with laser surgery. This procedure is called scatter laser treatment. Scatter laser treatment helps to shrink the abnormal blood vessels. Your doctor places 1,000 to 2,000 laser burns in the areas of the retina away from the macula, causing the abnormal blood vessels to shrink. Although you may notice some loss of your side vision, scatter laser treatment can save the rest of your sight. Scatter laser treatment works better before the fragile, new blood vessels have started to bleed. Even if bleeding has started, scatter laser treatment may still be possible, depending on the amount of bleeding. If the bleeding is severe, you may need a surgical procedure called a
vitrectomy. During a vitrectomy, blood is removed from the center of your eye. (NEI/NIH, 2013)

The National Eye Institute reports vision loss from diabetes can be prevented 90 percent of the time with early detection and regular dilated eye exams.

**Glaucoma**

Normally there is a constant production and drainage of fluid (aqueous humor), which gives the eye its shape and keeps the eye lubricated. But if excess fluid is produced, or if the drainage system falters, pressure increases in the eye. Eventually, this damages the optic nerve, which carries visual signals to the brain.

The gradual loss of sight begins on the outer edge, affecting peripheral vision. This is called chronic glaucoma, and accounts for about 90 percent of cases. Glaucoma can go undetected, because the increased pressure often is painless, stressing the importance of a regular dilated eye exam.

Rare acute glaucoma is characterized by severe headache or eye pain, and sudden loss of vision. People who experience acute glaucoma must receive immediate medical attention.

Immediate treatment for early-stage, open-angle glaucoma can delay progression of the disease. That’s why early diagnosis is very important. Glaucoma treatments include medicines, laser trabeculoplasty (to help fluid drain out of the eye), conventional surgery, or a combination of any of these.
While these treatments may save remaining vision, they do not improve sight already lost from glaucoma. (NEI/NIH, 2013)

**Macular Degeneration**

Macular degeneration is the leading cause of blindness in people over age 55. The macula, a tiny area in the center of the retina, contains millions of light-sensing cells that produce detailed central vision. As people age, the macula can deteriorate, causing a blurred or dark area in the center of the visual field.

There are two types of macular degeneration, and they commonly are referred to as “dry” and “wet.” The dry form is more common, and tends to progress more slowly than the wet.

The wet form is characterized by bleeding in and under the retina. The wet form often can be treated by injections. If you get this treatment, you may need multiple injections. Your eye care professional may give them monthly. Before each injection, your eye care professional will numb your eye and clean it with antiseptics. To prevent the risk of infection, a doctor may prescribe antibiotic drops. (NEI/NIH, 2013)

Another treatment is photodynamic therapy. This technique involves laser treatment of select areas of the retina. First, a drug called Verteporfin will be injected into a vein in your arm. The drug travels through the blood vessels in your body, including any new, abnormal blood vessels in your eye. Your eye care professional then shines a laser beam into your eye
to activate the drug in the blood vessels. Once activated, the drug destroys the new blood vessels and slows the rate of vision loss. This procedure takes about 20 minutes. (NEI/NIH, 2013)

Another option is laser surgery. Eye care professionals sometimes treat certain cases of wet macular degeneration with laser surgery, though this is less common than other treatments. This treatment is performed in a doctor’s office or eye clinic. It involves aiming an intense beam of light at the new blood vessels in your eyes to destroy them. However, laser treatment also may destroy some surrounding healthy tissue and cause more blurred vision. (NEI/NIH, 2013)

Both forms may impair reading, driving or anything that requires detailed sight. Usually a person’s peripheral vision remains, and can be enhanced with low-vision aids. There also is a rare congenital form of macular degeneration.

**Retinitis pigmentosa (RP)**

Retinitis pigmentosa is a progressive, inherited eye disease characterized by deterioration of the retina. RP usually is diagnosed at a young age. Typically it begins with night blindness, followed by a gradual loss of vision that starts on the edges and ends in tunnel vision.

Much research is going on worldwide in an effort to find a cure, but at this time there is no treatment for RP. RP progresses differently in each individual. Many people retain some useful vision, although it can lead to total
blindness. Usher Syndrome is a rare combination of RP and congenital hearing loss.

**Stroke**

Hemianopsia is loss of vision on one side of the eye due to stroke or brain tumor. If the right half of the visual field is gone, the damage is to the left side of the brain and vice versa. Vision loss from a stroke or tumor is usually permanent. Those affected by hemianopsia must often learn to compensate by turning the head to accommodate the blind side.

**TREATMENTS**

With any eye condition, early detection can be critical in determining types of treatment available. It is important to consult with your doctor about options.

**OPTICAL LOW VISION AIDS**

**Magnifiers**

Commonly called magnifying glasses, magnifiers can either be hand-held or freestanding. Hand-held magnifiers are lightweight and portable. They offer a larger viewing area than most other magnifiers. Freestanding magnifiers are heavier and less portable. They are placed directly on the material to be viewed. Both types can be purchased with a built-in light source.
There are two important things to understand about magnifiers. As magnification gets stronger, the percentage of the object you can see gets smaller. For example, when reading a book with a magnifier, the stronger the magnifier, the fewer words or letters you can read at once. Also, the stronger the magnification, the closer you must hold the magnifier to the object.

**Magnifying Spectacles**

Magnifying spectacles are stronger than ordinary glasses. Reading material must be held closer than with hand magnifier for focus. Though this may seem awkward at first, spectacles have the advantage of leaving your hands free.

**Telescopes**

Telescopes are used for distance magnification. A hand-held telescope may work well for spotting distant objects such as street signs, house numbers or aisle signs in the supermarket. When watching TV, a sporting event or a play, small telescopes mounted on eyeglasses may be helpful.

**TV Reading Systems**

TV reading machines are commonly called CCTVs, or closed-circuit televisions. When using these electronic devices, an object or book etc. is placed on a flat device in front of a screen. The CCTV scans the object you want to look at, and shows you an enlargement of it on the screen. CCTVs look somewhat like old microfilm machines. Some CCTVs hook
directly to an existing television, and others are standalone units.

A CCTV allows the viewer to control the size of the magnification, light, and contrast. CCTVs can show color or black and white. CCTVs often cause less eye fatigue than other low-vision devices.

**Lighting**

Appropriate lighting is extremely important for maximizing remaining vision. Refer to page 19 for more information.

**NON-OPTICAL LOW VISION AIDS**

There are numerous low-vision aids: large-print books, magazines; plastic template guides for writing checks, letters, and addressing envelopes; auditory devices including talking cell phones, tablets, computers, calculators, watches and clocks; playing cards with big, bold numbers, easy-to-read Bingo cards and many table games that are completely tactile. Adaptive devices are available from several sources. Contact Vision Loss Resources if you’d like some names. Note: Vision Loss Resources does not sell products.
ASPECTS OF VISION LOSS

Emotionally, vision loss is similar to other major life changes. It can be a difficult and trying time. For most, the adjustment to sight loss is a grief process.

While grief usually is associated with death and mourning, it occurs with any significant loss. This can be a physical loss such as vision, hearing, strength, or a life change such as moving, job loss or divorce.

Some theorists believe that in any loss, part of what we grieve is the loss of what we thought the rest of our life would be like.

The grief process doesn’t always proceed in organized stages; in fact, people often describe it as a roller coaster of emotion. Each of the feelings associated with grief has a purpose in helping the person adjust to the changes.

Vision loss often begins with a period or denial or disbelief. It may be difficult to accept that the loss is permanent, that medically nothing can be done or how much one’s personal life will be affected, especially reading and driving.

Actually, a period of denial or disbelief can be useful. It gives time needed to gradually adjust to the loss. Likewise, it allows time for the person to gather the inner strength and out resources needed to cope with the changes.
Guilt often is experienced in adjusting to vision loss. People wonder what caused the vision problems and may ask, “Did I read too much, or abuse my eyes in some way? If I had gone to the doctor sooner, or more often, would it have made a difference? I wish I had taken better care of myself!” These are examples of common responses to the question: “Why me?”

Usually there is nothing that a person did to cause sight loss, and most likely it could not have been prevented. Wrestling with these questions, however, helps a person come to terms with sight loss.

Of all the feelings in the adjustment process, anger and depression are the most common. Anger can range from mild frustration to extreme rage. Depression can range from feeling out of sorts to deep sadness and despair. Whatever the level of expression, such feelings are normal reactions in adjustment and grief. Whenever a major change or loss in life is sustained, self-esteem is temporarily diminished. As anger and depression are experienced and expressed, people start to be energized and self-esteem begins to be restored.

Other common feelings in adjustment include fear, rationalization, anxiety, isolation and even hopelessness. These are a natural part of the grief process, and it is important to have an outlet for them. One of the best prescriptions for dealing with vision loss is to have an opportunity to express feelings openly, without fear of pity or judgment. Often, someone else who has gone through a similar loss is most able to understand.
Family and close friends commonly experience the same feelings of grief as does the person with vision loss. These feelings may be expressed through frustration because someone they care about no longer can see to read or drive. They also may be uncertain about how much or in what way to help. Misunderstandings can occur. The words of a woman who has macular degeneration reflect the frustration many visually impaired people experience: “Let me do it myself, or at least try to do it, and if I need help, I will ask for it. Needing help with one thing doesn’t mean I need help with everything!”

Certainly all frustrating situations can’t be eliminated, but their occurrences can be minimized if the visually impaired person is allowed to be as independent as possible. Though well-intended, many times help is given it is not needed or appreciated. The opportunity to experiment with new ways of doing things, and the freedom to request assistance when it is needed, are essential for learning to live with vision loss. Patience and the ability to laugh at mistakes help make the adjustment process easier for everyone.

Losses in life can teach that we not only survive, but adapt, learn and grow. It is important to identify inner strengths and outer resources when adapting to vision loss.

The inner strengths come from understanding the adjustment process and courageously and creatively working through the feelings that accompany it. The outer resources can come from the adaptive techniques, training and services available
through Vision Loss Resources and other organizations for the blind. Services include independent living skills classes, equipment, support groups, and peer mentors. This combination of resources will help compensate for vision loss, and point the way to a full, productive life.

MEETING SOMEONE WITH VISION LOSS

Some people may feel uneasy at the prospect of talking with a person who is blind or visually impaired. Simply extend the same courtesies and respect to people who are blind or visually impaired that you would to anyone you meet. Keep in mind that each person is an individual and that eye conditions vary from person to person. Some guidelines may need to be adapted to suit the abilities, preferences and needs of the individual with vision loss.

Introduce yourself. Speak upon entering a room or area where there is a visually impaired person. In many instances, the person will offer a hand for you to shake when meeting for the first time. Make sure they know when you're leaving a space - don't leave someone talking to an empty room!

Do not shout. Speak in a normal and comfortable tone.

Speak directly. Speak to the person and not to or through a third party. Visually impaired people can speak for themselves.
Avoid cues that depend on vision. Remember that nods, shrugs and hand gestures may not be noticed as clues to what you are conveying. Be specific when giving directions. For example, “to the right of your plate” or “three blocks north” are helpful phrases.

Do not move objects. Do not move personal items or rearrange furniture. All cabinet, closet and room doors should be fully opened or fully closed. Always push chairs back under tables.

Don’t avoid certain words. Do not avoid words like blind, look, see, watch, etc. These words are part of everyday conversation and are not offensive.

Guide Dogs. Remember that guide dogs are working dogs. Whenever the dog is in harness it should not be petted or even talked to as this could distract the dog.

Offering Assistance

People who are blind choose the areas of their lives in which to remain independent and the areas in which they welcome assistance. There are many ways in which you can be helpful to a blind person in everyday situations, but always ask first if the person wishes assistance.

Describing unfamiliar settings. Be brief and proceed in order, starting with the scene directly facing the person, and move to the right, behind and left.

Dining out. When you dine with a visually impaired person, offer to read the menu (with prices) if the restaurant doesn’t
provide a Large Print or Braille menu. The location of food servings can be described as numerals on a clock face: “Potatoes at 2, fish at 6.”

**Reading.** If asked to read something for a person, make sure to read all materials clearly as they appear on the page. Do not read excerpts or summarize unless the visually impaired person requests you to do so. Read clearly and at a comfortable pace. If asked to read longer items, such as newspapers, magazines, menus etc. simply start with a table of contents or similar listing of topics and let the person choose which areas they want you to read in detail.

**Monetary transactions.** There are techniques people use to identify money. If you have a money transaction, name each bill so that he or she may fold it according to the individual's own method for identification. Coins do not need to be named as they can be distinguished by touch.

**Sighted guide.** This technique is widely accepted as the safest, most efficient way for a person with a visual impairment to walk with a sighted person.

Always ask the person first if they would like sighted guide assistance. The guide should never push, pull or grab the visually impaired person, except in an emergency. Being grabbed or pushed can be startling, disorienting and potentially embarrassing.

To begin, the visually impaired person gently takes the guides’ arm just above the elbow, with four fingers on the inside of the arm and the thumb on the outside. The guide’s arm
remains relaxed at the side while the visually impaired person’s arm is held close to the side with a 90-degree bend at the elbow.

Walking together at a normal pace, the guide stays half a step in the lead, and describes landmarks and things of interest. The guide also must alert the visually impaired person to potential obstacles—stationary objects, narrow passages, doors, steps and irregularities on the pavement or floor surface.

Stairs and curbs should be approached squarely, never at an angle, and the guide should announce whether the steps go up or down.

Before proceeding, it is important to pause and give the visually impaired person time to take hold of the handrail and locate the edge of the first step with her or his foot. On stairs, the sighted guide stays one step ahead. The guide should not count the steps, but may mention when there is one step left.

Once you’ve reached the destination and described the surroundings, it’s time to break contact. Before you do that, put the person in touch with an object such as a wall or piece of furniture; if you fail to do that, they may find it disorienting and nerve-wracking.

For additional training on Sighted Guide technique, contact Vision Loss Resources at 612-871-2222.
TIPS FOR MAKING A HOME ACCESSIBLE

Whether home is a house, apartment or single room, simple adaptations can be made to enhance safety and independence.

**Lighting:** Appropriate lighting is extremely important for maximizing remaining vision. It will take experimentation to discover the best lighting conditions for each person. Here are some tips:

- Make sure the light is always aimed directly at what you are trying to see. A gooseneck lamp with an adjustable arm works well.

- Experiment with light bulbs of varying intensities to determine the brightness that is most comfortable. Bright light that improves vision for some will have the opposite effect for people whose eyes are light-sensitive.

- Try different types of lighting – incandescent, fluorescent and halogen – to see which is preferred.

- Eliminate glare by placing mirrors and other shiny objects where light will not reflect off them. Wearing wrap-around sunglasses or a visor may also help to reduce glare.

- Use adjustable window coverings, horizontal or vertical blinds for example, to regulate the amount of natural light entering room.
**Living Area:** With the simple changes described below, a living area can be made safer and more convenient.

- Arrange furniture to accommodate normal traffic patterns and move large pieces out of main traffic areas.

- Make sure there is adequate lighting near the furniture. Floor lamps are useful because they can be moved easily.

- Place brightly colored accessories – tablecloths, pillows, centerpieces – on furniture to make it easier to locate.

- Remove throw and area rugs or make sure they are securely fastened to the floor.

- Avoid choosing furnishings and floor coverings with busy patterns, as items can get visually ‘lost’ in them.

- Have someone mark frequently used settings on the thermostat and appliances with a material that can be felt. Puff-Paint, available in craft stores, and a product called Hi-Marks work well. Velcro and raised bump dots are also helpful. For more information, contact Vision Loss Resources. (We do not sell any products.)

- Use highly contrasting colors to make objects more visible. For example, use paint in a contrasting color to mark the edge of steps or to accentuate a handrail. Place a black switch plate on a white wall, or install knobs that contrast in color with the doors.
Organize: Get rid of unnecessary items and work out a system for locating the essentials.

- When you move furniture or any belongings—a chair at a table or a coffee cup—be certain to return them to their designated place. Ask guests and family members to do the same thing.

- Avoid accidents by closing doors to cupboards and the dishwasher. Make sure that doors between rooms are either completely open and flush with the wall, or completely closed.

- Purchase appliances and electrical equipment that have dials or buttons that can be identified by touch, rather than electronic touch-pad controls which are smooth and may be difficult to operate.

- Make sure that controls are easy to reach. For example, a stove with controls on the front will be safer and easier to use than one with controls at the back that require a visually impaired person to reach over hot burners to operate.
RESOURCES

Contact Vision Loss Resources for information about:

Audio News Services
Audio news services are available via a phone dial-in service or special “talking” radio.

Audio Description
Audio description is the descriptive narration of key visual elements within a TV show, movie or live play.

Community Center
Recreational, leisure, and educational activities such as arts and crafts, games, classes, outings and fitness are available through the Community Center at Vision Loss Resources and other centers.

Financial Resources
Assistance with bill organization, writing of checks, etc.

Home Repair and Chore Services
Referrals to agencies providing home services.

Library
Large-print, Braille and audio books and magazines are available free of charge on loan through the National Library Service for the Blind and Physically Handicapped.
Low Vision Clinic
Low vision refraction test, magnification, and assessment.

Low Vision Products
We do not sell products, but we can give you information on stores or online stores that sell assistive devices and services.

Museums
“Hands-on” tours are available at many museums for people who are visually impaired. We can give you information.

Shopping Resources
Personal shopping assistance, grocery delivery and other community resources.

Support
Vision Loss Resources offers support groups and peer mentors.

Technology
Classes on accessible devices such as phones and tablets are offered at Vision Loss Resources.

Transportation
Help with locating resources and assistance with completing applications for transportation services.
CONCLUSION

This publication is designed to help those with vision loss and those who care about them. Its goal is to build understanding and enrich the lives of those with vision loss.

Vision Loss Resources (formerly Minneapolis and St. Paul Societies for the Blind) was founded in 1914. We are Minnesota’s leading provider of information and referral, rehabilitation and support services for individuals who are blind or visually impaired. Vision Loss Resources is a private, non-profit, United Way-affiliated organization.

Contact Vision Loss Resources for additional information and to learn how we can help you or someone close to you.

VISION LOSS RESOURCES

West Metro Office
1936 Lyndale Avenue S.
Minneapolis, MN 55403
612-871-2222 (V/TTY)

East Metro Office
216 S. Wabasha Street
St. Paul, MN 55107
651-224-7662

Website: www.visionlossresources.org
E-mail: info@vlrw.org