



Fact Sheet: **Vision Loss and Blindness**

Nearly 3.5 million Americans over 40 have some degree of vision loss, most commonly from age-related conditions. This number is expected to double in the next few decades as the baby boomers grow older.

Most people with age-related vision loss will not become completely blind; instead they will experience partial or moderate loss of vision. They may need to develop new skills to remain self-reliant. This Fact Sheet discusses age-related vision loss and how you, as caregiver, can help your loved one adjust to the challenges.

What causes adult-onset vision loss?

Most people experience some decline in vision as they age. It becomes more difficult to read small print, to get around in dim lighting, or to tell the difference between dark blue and black, for example. Such changes in vision are a normal part of aging. However, more serious changes to eyesight also occur as one ages.

People of any age who have a stroke, traumatic brain injury, or a brain tumor may experience many physical changes, including vision loss. The loss may be temporary or permanent.

Most older adults experiencing low vision, however, will be affected by one of four conditions: *macular degeneration, glaucoma, cataracts* and *diabetic retinopathy*. The table below summarizes the most common symptoms or warning signs of these conditions; more detailed information follows.

Conditions	Most Common Symptoms & Warning Signs
Macular Degeneration	Vision loss in center of eye; blurred vision; straight lines look wavy; need for more light; affects one or both eyes
Glaucoma	Gradual loss of peripheral, or side, vision; difficulty driving at night; loss of contrast
Cataracts	Hazy vision; difficulty driving at night; double vision; trouble distinguishing colors; sensitivity to glare
Diabetic Retinopathy	Blurred or changing vision; difficulty reading; floaters; affects central or peripheral vision

It is important to remember that a person may have one of these

conditions but not have any or all of the symptoms listed in the table above.

Macular Degeneration

What is it?

Age-related macular degeneration (AMD) is the leading cause of vision loss for people over 50 in the Western world. There are two types of macular degeneration, the wet form and the dry form.

Dry macular degeneration is the more common form of the condition and develops slowly. Vision loss may be mild for years, although it will eventually worsen. It may also lead to wet macular degeneration. With dry macular degeneration, small fatty deposits called drusen gather on the macula, which is a part of the eye that helps us see sharp details.

Wet macular degeneration is more severe and accounts for about 10 percent of cases of macular degeneration. It is caused by the growth of abnormal blood vessels under the macula. These blood vessels leak blood into the tissue at the back of the eye, producing scar tissue and rapid changes to the macula. Wet macular degeneration often develops very quickly and causes sudden loss of vision in the center of the eye.

One unusual effect of rapid vision loss is called Charles Bonnet Syndrome. This condition, which sometimes accompanies macular degeneration, produces hallucinations. These hallucinations do not reflect mental illness or another neurological disorder; they are, in effect, occasional visual

“additions” to limited sight, and may even be pleasant—flowers, animals, faces. An estimated 10 to 40 percent of those with AMD experience this syndrome.

Treatment Options

There is no cure for macular degeneration, but early detection means more treatment options may be available and research into the condition is ongoing. While there are currently no direct treatments for dry macular degeneration, there are some recommendations to follow which may help slow the progress of either the wet or dry form. These include stopping smoking, eating lots of vegetables and fruits, especially dark green leafy vegetables (such as spinach, kale and collards) and taking, with your doctor's approval, supplements with zinc, copper and anti-oxidant vitamins (vitamins C, E and beta carotene). The National Eye Institute is studying other supplements that can affect eye health including omega-3 (fish oil), lutein and zeaxanthin.

Wet macular degeneration can be treated, and early detection and treatment may prevent severe vision loss. Medications currently available are delivered to the eye by injection. These treatments help reduce the growth of abnormal blood vessels and help preserve, or in some cases improve, the vision that remains. Other options, used less frequently, include photodynamic or laser surgery; additional options are under investigation. For most people, therapies require multiple treatments, and can result in slower loss of vision.

Glaucoma

What is it?

Glaucoma causes the loss of peripheral, or side, vision caused by optic nerve damage usually associated with high eye pressure. Glaucoma is a leading cause of blindness in the U.S. and while it can affect people of all ages, it is most common in older adults. It is important that the symptoms of glaucoma are caught early, through screening by an eye care professional, to prevent total blindness.

Treatment Options

The damage caused by glaucoma is permanent, but treatments are available to prevent further vision loss. The most common treatment for glaucoma is eye drops used daily to lower eye pressure. These medications can preserve vision but may cause side effects. Laser and conventional surgery are also sometimes options to treat glaucoma.

Cataracts

What is it?

A cataract is the clouding of the normally clear lens of the eye. This clouding causes hazy vision, as if you were looking through a frosted or yellow window. Cataracts typically develop gradually over a period of years and are a common cause of vision loss among older adults.

Treatment Options

Cataracts can be removed through surgery in which the lens of the eye is removed and replaced by a plastic lens.

This operation is fairly short and is highly successful. After surgery, patients often have a change in their eyeglass prescription. However, some individuals are not bothered too much by their cataracts and are able to manage by changing eyeglass prescriptions and protecting their eyes from too much sunlight, as exposure to sun speeds up the growth of cataracts.

Diabetic retinopathy

What is it?

Diabetic retinopathy can occur in people with diabetes, typically in those with advanced diabetes and high blood sugar levels. Diabetic retinopathy is caused by leaking blood vessels. An estimated 25 percent of people with diabetes have some diabetic retinopathy, but for most no severe vision problems will develop. Because there are often no symptoms in the early stages of diabetic retinopathy, people with advanced diabetes should have regular vision exams to check for this condition.

Treatment Options

Maintaining stable blood sugar levels is the best way for a diabetic to prevent diabetic retinopathy. Once the condition has developed, laser surgery can sometimes prevent further vision loss. Advanced retinopathy can be treated through microsurgery called vitrectomy which removes and replaces eye fluid.

Getting an accurate diagnosis

The National Eye Institute and the American Academy of Ophthalmology recommend that everyone over age 60

get a full, dilated eye exam every two years, or more often if there is an eye disease involved.

If your loved one experiences the symptoms of low vision, such as blurred vision or sensitivity to glare, he or she should seek the care of a low vision specialist—an optometrist or ophthalmologist with particular expertise in this area. (See the *Resources* section to find a specialist.) This specialist will do a vision assessment and then make a referral for specific treatment, vision-related training and/or assistive devices.

It is important that your loved one continues to see the vision specialist every year to catch any changes in vision. The sooner such changes are found and possibly treated, the better the chance that your loved one will still be able to retain his or her vision and live as independently as possible.

Vision-related rehabilitation services and vision training

Helping your loved one find vision-related rehabilitation services may be one of the best ways for you as a caregiver to provide practical support. Rehabilitation services include adaptive living, orientation and mobility training (including the possibility of using a cane to move around in public), vision training, and assistive devices.

Because some people with low vision do still retain usable vision, it's helpful to work with a vision rehabilitation specialist to learn how to best use the vision they have. If your loved one has macular degeneration, for example, and has lost vision in the center of his or her eye, the vision rehabilitation specialist

will teach how to best use the peripheral vision that remains.

Rehabilitation services are provided by state and private agencies serving blind and visually impaired persons. You can locate these services by checking your local telephone directory, or calling the American Foundation for the Blind for a referral (see the *Resources* section for more information).

Home Alterations (Adaptive Living)

There are many inexpensive and relatively simple changes that you can make in the house to help your loved one remain safe and comfortable.

- **Improve lighting and reduce glare**

Adding more lamps and lighting throughout the house will help your loved one use their remaining vision effectively. Consider adding gooseneck lamps in places where extra light is needed for such tasks as writing checks, cooking or reading. Illuminate stairs, especially top and bottom steps. Install night lights in key places.

It is useful to find out which types of bulbs provide the best kind of lighting to help your loved one see most clearly. Depending on the type of vision loss, different qualities of light (more white or yellow, for example) might make it easier to see.

Reducing glare is important as well. Installing blinds or shades

on windows in the house and wearing anti-glare sunglasses and visors outdoors will be beneficial.

- **Accentuate dark and light contrasts throughout the home**

Many alterations are simply ways to make things show up more easily. Use paint or tape in contrasting colors to help your loved one find and use items throughout the house. For example, having outlet or switch plate covers in colors that contrast with wall paint makes light switches or thermostats easier to find. Similarly, using plates, cups and utensils in a color that contrasts with the countertop and table aids in food preparation and dining. Use towels in the bathroom that do not blend with the wall color to make them easy to find. Install handrails along the staircase in colors that contrast with walls to help prevent falls.

- **Organizing the house**

Organize cupboards and specify exact locations for important things. If the cereal is *always* on the middle shelf of the pantry, for example, your loved one will not need to strain to try to determine if it is cereal or something else. Set up consistent places for mail, keys and other important items.

Use markers to print large labels for such everyday items as cleaning or cooking supplies (and be sure to keep cleaning supplies separate from food

storage areas). Clearly mark stove dials and label all medications.

It's extremely important to keep your living space clear of obstacles and hazards. While large area rugs can be useful to define rooms, remove throw rugs and unnecessary furnishings that clutter walking paths to help eliminate tripping hazards. Any measure you can take to reduce the danger of falls is helpful.

Assistive devices

Many kinds of assistive devices can be of great help and often can be found at drugstores or specialty shops or through websites that specialize in these products. Some of the most useful are:

- **Magnifiers.** Very effective for those with low vision and come in many different sizes and styles. Different kinds of magnifiers will help accomplish different tasks.
- **Penlights.** Useful whenever more concentrated light might help your loved one see or read something. Like magnifiers, you might want to keep several penlights around to help in different situations.
- **Electronics.** Closed circuit televisions (**CCTVs**) are very useful for those with low vision. CCTVs look something like a computer but consist of a camera and screen. An object can be placed under the camera which magnifies it, and then displays it much larger on the screen. This makes reading and writing easier.

- There are also a large number of **audio products** to help with everyday tasks or hobbies. These include “talking” clocks, calculators, watches, navigation tools, books and more.
- **Telephones** come with large dials and buttons in various forms; **computers** offer large print, large screens and special keyboards. Many other ingenious devices have been developed to help; see the **Resources** section of this fact sheet and the Family Caregiver Alliance *Fact Sheet on Assistive Technology* for more information.
- Carry magnifiers and/or penlights when shopping or going to appointments outside the home.
- Fold each denomination of dollar bill a different way to help your loved one shop or use public transportation.
- When needed, let bus drivers, shopkeepers or others know that your loved one has low vision to make traveling outside the home safe.

Traveling outside the home (orientation and mobility training)

Vision rehabilitation services introduce techniques to make travel as independent as possible. This is called orientation and mobility training, and will include learning how to best use existing vision. Other techniques include using a white cane, and learning how to better use one’s hearing while walking. While not everyone is eager to use a cane, if your loved one is receptive, this can be a very useful tool to maintain independence.

To assist someone while walking, use the *sighted guide technique*: walk a half step in front of them and have them hold your arm just above the elbow. You can also announce any hazards, like steps or holes in the sidewalk to help them (and you!) avoid falling. Other tips:

Paying for low-vision care and devices

Medicare covers only certain low-vision care, including some surgery for glaucoma and for intraocular lenses used in cataract surgery. It also pays for treatment for certain patients with age-related macular degeneration in which the central part of the eye deteriorates.

Some nonprofit groups also provide financial assistance to needy patients with low vision. The **Resources** section of this fact sheet lists organizations which provide financial aid for eye care or assistive devices.

Emotional effects of vision loss

Anyone diagnosed with a condition causing vision loss may experience many difficult emotions, including grief, shock, anger and depression. These feelings may last only a short time or could persist for years. Losing the ability to drive may be an emotional blow, and your loved one may worry about whether he or she will still be able to live independently. Vision loss might be one of the first definite signs of aging that

people experience, making them feel vulnerable or frail.

Acknowledging these negative emotions is important. As a caregiver, you may also have concerns about how your relationship with your loved one will change. You might be worried about increased dependence. You might be unhappy about being asked to take on tasks that you do not want to do. You will most likely experience emotions about your loved one's vision loss that you will need to address. Being open and honest about these feelings will help you move past them and allow you to continue as a caregiver.

Most people with vision loss do find that their confidence about living with reduced eyesight increases over time. By participating in rehabilitation training and trying the techniques taught there, your loved one will likely begin to trust their new skills and feel better about the future.

How can you help your loved one adjust to low vision?

To help your loved one deal with the challenges of reduced vision, you'll want to be as informed, supportive and caring as possible. Learning as much as you can about the condition and best adaptation strategies will help reduce early feelings of despair or fear, and move to acceptance and confidence. Counseling and support groups can be significant sources of help. Finally, by treating the vision loss as a family issue you will help your loved one feel supported as he or she adjusts to life with vision loss.

It might not be obvious where or when your loved one needs assistance.

Although it's hard for any of us to ask for help, communicating openly and clearly is important. Encourage your loved one to be specific about the kinds of tasks that she or he finds challenging and exactly what you can do to help.

Remember that you may need to use speech in specific ways to tell your loved one things. For example, upon leaving the room you may need to let them know you are going. Similarly, when greeting people, you may need to announce who someone is, as your loved one might not be able to recognize them. Also, remember that pointing, nodding the head or using other body language will not be effective communication.

Although your loved one now has a vision impairment, it is very important to encourage self-reliance. By continuing to treat your loved one with respect and care, you can help him or her feel empowered to overcome challenges and remain as independent as possible.

Recommended Reading

Aging and Vision Loss: A Handbook for Families, Alberta L. Orr, MSW and Priscilla A. Rogers, PhD, 2006, AFB Press. www.afb.org.

Living Better: A Guide for People with Vision Loss, Lighthouse International, 2008. www.lighthouse.org.

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Assistive Technology

Resources

Organizations that provide general information about low vision:

American Foundation for the Blind

2 Penn Plaza, Suite 1102
New York, NY 10121
(800) AFB-LINE (232-5463)
www.afb.org

Discovery Eye Foundation

8733 Beverly Boulevard, Suite 201
Los Angeles, CA 90048
(310) 623-4466
www.discoveryeye.org

Lighthouse Guild

15 West 65th Street
New York, New York 10023
(800) 284-4422
www.lighthouseguild.org

National Eye Institute National Institutes of Health

31 Center Drive MSC 2510
Bethesda, MD 20892
(301) 496-5248
www.nei.nih.gov

Organizations that provide more information about specific conditions:

AMD Alliance International

111 East 59th Street
New York, NY 10022
(212) 821-9200
www.amdalliance.org

The Glaucoma Foundation

80 Maiden Lane, Suite 700
New York, NY 10038
(212) 285-0080
www.glaucomafoundation.org

The Macular Degeneration Partnership

A program of the nonprofit Discovery
Eye Foundation
850 Health Sciences Road
Irvine, CA 92697
(310) 623-4466; (888) 430-9898
www.amd.org

Organizations that provide financial aid or products for eye care:

BrightFocus Foundation

22512 Gateway Center Drive
Clarksburg, MD 20871
(800) 437-2423
info@brightfocus.org
www.brightfocus.org

Eye Care America

(877) 887-6327
eyecareamerica@aao.org
www.eyecareamerica.org

Lions Clubs International

300 W. 22nd Street
Oak Brook, IL 60523
(630) 571-5466
www.lionsclubs.org

Mission Cataract USA

PMB211, 1099 E. Champlain Drive,
Suite A
Fresno, CA 93720
(559) 797-1629
www.missioncataractUSA.org

Vision USA

243 North Lindbergh Blvd., Floor 1
St. Louis, MO 63141
(800) 365-2219 ext. 4200
www.aoa.org/x5607.xml

Organizations that may help find low-vision specialists:

American Academy of Ophthalmology

P.O. Box 7424
San Francisco, CA 94120-7424
(415) 561-8500
www.aaopt.org

American Optometric Association

243 North Lindbergh Blvd
Saint Louis, MO 63141
(800) 365-2219
www.aoa.org

Resources for Caregivers

Southern Caregiver Resource Center

3675 Ruffin Road, Suite 230
San Diego, CA 92123
(858) 268-4432; (800) 827-1008 (in CA)
Fax: (858) 268-7816
E-mail: scrc@caregivercenter.org
Web site: www.caregivercenter.org

The Southern Caregiver Resource Center offers services to family caregivers of adults with chronic and disabling health conditions, and is for residents of San Diego and Imperial counties. Services include information and referral, counseling, family consultation and case management, legal and financial consultation, respite care, education and training, and support groups.

**Family Caregiver Alliance
National Center on Caregiving**

235 Montgomery Street, Suite 950
San Francisco, CA 94104
(415) 434-3388; (800) 445-8106
Web site: www.caregiver.org
E-mail: info@caregiver.org

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy. FCA's National Center on Caregiving offers information on current social, public policy and caregiving issues, provides assistance in the development of public and private programs for caregivers, publishes timely reports, newsletters and fact sheets, and assists caregivers nationwide in locating resources in their communities.

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