

CARING FOR THE VISUALLY IMPAIRED

A Handbook of Resources for the Informal Caregiver

Compiled by Dan Roberts



Lowvision.preventblindness.org

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LIVING WELL WITH LOW VISION

The mission of Living Well With Low Vision is to make it as easy as possible for people to educate themselves about loss of vision and to meet the daily challenges resulting from it. By empowering individuals, we hope to provide practical ways for people to improve the quality of their daily lives and relieve the emotional trauma that often accompanies low vision.

Find out more at lowvision.preventblindness.org.

ABOUT PREVENT BLINDNESS

Founded in 1908, Prevent Blindness is the nation's leading volunteer eye health and safety organization dedicated to fighting blindness and saving sight.

Focused on promoting a continuum of vision care, Prevent Blindness touches the lives of millions of people each year.

ABOUT DAN ROBERTS

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There are four kinds of people in the world: those who **have been** caregivers, those who are **currently** caregivers, those who **will be** caregivers, and those who **will need** caregivers. –Rosalynn Carter

This booklet is intended to assist those who are unselfishly committed to caring for visually impaired individuals. We hope the information gathered here will be of value to those special caregivers as they share the challenges confronting their loved ones and friends.

Our thanks goes to all of those organizations and individuals who have made these resources available.

Dan Roberts
Editor in Chief,
Living Well With Low Vision

WHO ARE CAREGIVERS?

Formal caregivers are volunteers or paid care providers associated with a service system. **Informal caregivers** are family, friends, neighbors or church members who provide unpaid care out of love, respect, obligation or friendship to a disabled person. These people far outnumber formal caregivers, and without them, this country would have a difficult time formally funding the caregiving needs of a growing number of disabled recipients.



Up to 20% of the total population is providing part-time or full-time care. The typical informal caregiver is a daughter, age 46, with a full-time job, providing an average of 18 hours per week to one or more of her parents.

Among adults aged 20 to 75, providing informal care to a family or friend of any age, 38% care for aging parents and 11% care for their spouse. About two-thirds of those caregivers for people over age 50 are employed full-time or part-time. Two-thirds of those, about 45% of working caregivers, report having to rearrange their work schedule, decrease their hours, or take an unpaid leave in order to meet their caregiving responsibilities.

(Source: National Care Planning Council at www.longtermcarelink.net)

A CAREGIVER IS NOT A CARETAKER

A CAREGIVER:

- gives freely
- honors personal boundaries
- does not judge
- takes positive action
- allows the receiver to activate his or her own capabilities
- respectfully waits to be asked for help
- practices good self-care to be of better service to others
- focuses on the solution, not the problem

(Source: "Codependency: Caretaking vs. Caregiving" by Elizabeth Kupferman, RN, LMHC, LPC www.expressivecounseling.com)

Caregiving can be an important part of any level of the continuum of care, from **informal family care** in the home to **professional end of life care**.

Unfortunately, family caregivers do not often receive training in how to deliver complicated care, nor do they take advantage of **resources** and **support services** that can help them be more effective partners with their loved ones...

...and if the care recipient is visually impaired, that can add considerably to the responsibility.

THE CAREGIVER'S "NEEDS PYRAMID"



(Reference and image source: "Care for the Caregiver: Information, Simplification, Peace of Mind (And Time)" by Stephan G. Wiet, Ph.D. (Johnson & Johnson Patient Assistance Foundation, Inc. at www.strengthforcaring.com)

Psychologist Stephen G. Wiet, Ph.D., has designed a helpful pyramid concept illustrating solutions that can help caregivers. The pyramid has four parts, with the foundation being "Help Me Make Better Decisions". According to Dr. Wiet, a caregiver is constantly searching for answers to legal, medical, healthcare professional and financial questions.

Since personal time is usually at a premium, be sure to take full advantage of all the resources available, as they can help you to make informed decisions quickly and easily.

The next part is "Simplify My Life". Prioritize tasks and take them on one at a time. And, of course, always be on the lookout for products, solutions, and services that will help.

This kind of approach can then lead to the next part of the pyramid, "Peace of Mind". That's when the caregiver can feel more free to shift from the needs of the recipient to other obligations, such as attentiveness to work or other family members. Sometimes this stage is possible only when the caregiver has additional help or support systems, such as an eldercare community center, or a visiting healthcare professional.

The ultimate goal at the top of the pyramid is "Time for Me". Solutions that allow time for personal pampering result in healthier, more emotionally stable caregivers. And that can have only a positive effect on the recipient.

THE CAREGIVER'S LOW VISION T.A.S.K. FORCE

T. A. S. K. stands for the four elements of success in living with low vision. Caregivers play an important role in putting the T.A.S.K. Force into action.

TENACITY: the determination to explore new directions. The care recipient's quality of life can be maintained if the caregiver is persistent in searching for the tools and resources needed to overcome obstacles.

ADAPTABILITY: a willingness to change ways of doing things. A person usually has no choice when it comes to losing vision, but there are choices when it comes to living with it.

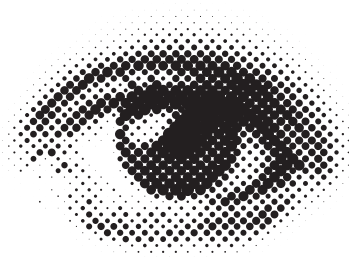
SUPPORT: from which comes "cope-ability." Caregivers, family members, friends, and organizations can provide the understanding and assistance needed to cope with low vision.

KNOWLEDGE: the most effective defense against the onslaught of vision loss. Knowledge puts a face on the enemy and a powerful weapon in our hands.

For more in depth about the Low Vision T.A.S.K. Force, see
[www.mdsupport.org tutorials/task.pdf](http://www.mdsupport.org/tutorials/task.pdf)

(Source: "The First Year--Age Related Macular Degeneration" by Daniel L Roberts (Da Capo Press; August 2006)

WHAT IS VISUAL IMPAIRMENT?



Visual impairment is ranked third behind arthritis and heart disease as the most common condition causing a need for assistance with activities of daily living for persons 70 years and older. It is, however, often overlooked in the home care setting when treating patients for other conditions.

(Source: A caregiver's eye on elders with low vision (abstract). Warnecke P. (Care, 2003 an;22(1):12 5.)

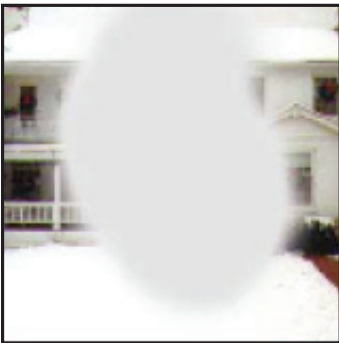
Also called low vision, it is defined as loss of eyesight that cannot be corrected with glasses, medicine, or surgery. It makes everyday tasks such as reading, shopping, recognizing faces, and even crossing the street difficult. Some signs to look for that may indicate visual impairment are:

- slowness in responding or moving
- confusion in environments with low contrast or low lighting
- confusion with faces and identifying people
- difficulty locating objects that are small or low contrast
- difficulty paying attention
- avoiding activities requiring good vision
- making mistakes in tasks that have small details
(i.e. taking wrong medicine)
- fear of falling

(Source: Mary Warren, MS, OTR/L SCLV, FAOTA (University of Alabama at Birmingham)

COMMON PATTERNS OF VISION LOSS

Everyone experiences vision loss differently, even those who share the same conditions. Most chronic diseases begin with no symptoms, then progress through various stages of blurriness, distortion, dim areas, and finally, blind spots in either or both eyes. These illustrations represent the end stages of the diseases described.



Age related macular degeneration (AMD) blurs the center of vision, degrading detail of objects, print, and faces. Peripheral (side) vision remains intact and can be used effectively. It is most common in people age 60 and older, but there are juvenile forms.



Diabetic retinopathy is caused by abnormal leakage and/or growth of blood vessels in the back of the eye (the retina). It may occur in anyone affected by diabetes, and it can affect both central and peripheral vision.



Glaucoma is a disease of the optic nerve, which carries the images we see to the brain. It is usually associated with elevated pressure in the eye. When damage to the optic nerve fibers occurs, blind spots develop that usually go undetected until significant damage is done.

Stroke is not actually an eye disease, but it can seriously impair vision. It results from rupture or blockage of a blood vessel in the brain, depriving parts of it of adequate blood supply. Various symptoms may occur,

depending upon the site and extent of damage. It affects the visual messages coming from both eyes, usually eliminating perception of either the right or left halves of the visual field. Detail vision may not be reduced, but reading may be difficult.

(For more about diseases affecting the eye, see www.mdsupport.org/audiovisual-library)

Whatever causes visual impairment, the end results are the same.

Seeing is difficult, but some vision usually remains. Total blindness occurs in only about 5% of the visually impaired population.



A person with low vision uses both visual and nonvisual cues, depending upon the amount of

eyesight present. Training

in developing and using other senses is helpful. To read “A Self Help Guide to Nonvisual Skills” online, see lowvision.preventblindness.org/publications.

Patience is important, as it may take longer to accomplish certain activities.

Depression is common in people with visual impairment, and it can be debilitating. For more important information, enter the keyword “depression” at lowvision.preventblindness.org/library.

ABCs OF CARING FOR THE VISUALLY IMPAIRED



A DOZEN HELPFUL HINTS

1. Use contrasting colors, such as black/white, black/yellow, or blue/yellow. Limit the number of colors, as too many can be confusing.
2. When communicating in writing, avoid cursive, and use a dark bold pen or marker--not a pencil.
3. When communicating by e-mail in rich text, set the font size to at least 16 points, and use easy-to-read fonts like Verdana or Arial.
4. Take time to learn about low vision technology and devices. Start by going to MD Support's Audio/Visual Library at www.mdsupport.org/audio-visual-library.
5. Learn simple ways to help the recipient adapt the home environment for safer and easier living. Many ideas will be found in the "Self-Help Guide to Non-Visual Skills" at <http://lowvision.preventblindness.org/publications>.
6. Help the recipient see with his or her ears by describing locations, people, and objects.
7. Use the "clock face" method to help the recipient locate food on the plate.
8. Include the recipient in social events, and encourage participation in a support group. See www.mdsupport.org/support/affiliates to find one locally.
9. When guiding, allow the recipient to maintain contact by grasping your arm. On stairs, remain one step ahead.
10. When guiding to a seat, allow the recipient to touch the chair or bench first, then seat themselves. Some verbal description by you of the style of seating might be helpful.
11. Emphasize the importance of good nutrition and exercise. Several good presentations on these topics are at www.mdsupport.org/audio-visual-library.
12. Low vision rehabilitation by a trained professional is an important part of the continuum of care for low vision individuals. For complete information, see <http://lowvision.preventblindness.org/library/low-vision-rehabilitation>.

B STRESS TRIGGERS

A caregiver may assume that the care recipient is more impaired than is actually the case. If so:

- › The caregiver may take over tasks the recipient might otherwise be able to handle.
- › The recipient may become over-dependent on the caregiver.
- › The recipient may feel that his/her autonomy and personal choice is being compromised or removed altogether.
- › The caregiver may feel burdened or taken advantage of.
- › Erosion of the original relationship may occur, adding stress to both parties and possibly having a negative impact on the health and/or safety of one or both persons.



The caregiver may be coping with frailties or limitations of his or her own.

The caregiver may be caught in a “sandwich” situation caring for both a younger child and an aging loved one. If so:

- › It can mean added stress for the caregiver as the recipient struggles to deal with growing personal limitations.
- › It can cause feelings of guilt and frustration for the older recipient, who may feel he or she is adding to the caregiver’s problems.

(Source: “Serving Older Persons with Visual Impairments and Their Caregivers-- Suggestions for State Units on Aging”. Greg Link, BA (National Association of State Units on Aging, July 2002)

Care for yourself first, and connect with other caregivers for support. Find links to caregiver support groups at www.medicare.gov/caregivers. Find caregiver respite services at archrespite.org/respitelocator.



THE RULES OF VISION ETIQUETTE

1. Speak in a natural conversational tone. It is not necessary to speak loudly, but enunciation is important, as we may not be able to see your lips.
2. Address us by name when possible, especially in crowded places.
3. Address us personally, not through someone else.
4. Greet us when we enter the room so we know you are present.
5. Indicate the end of a conversation when you leave us so we aren't left talking to the air.
6. Feel free to use words that refer to vision. We also use the words "see," "look," "watch," etc.
7. Do not leave us standing in "free space" when you are acting as a guide.
8. Be calm and clear about what to do if you see us about to encounter a dangerous situation.
9. If you think we need help, ask first. Do not assume your help is wanted.
10. When offering assistance, never take us by the arm. If you offer your arm instead, we can follow slightly behind and anticipate changes.
11. Never take hold of a white cane.
12. Never pet or interfere with a guide dog while it is on duty.

"We are more than our eyes."

Donald C. Fletcher, M.D.

(Source: Carl Augusto, President, American Federation for the Blind in New York, and David McGown, executive director of the Guild for the Blind in Chicago)

MAINTAINING INDEPENDENCE AND QUALITY OF LIFE

The “English Longitudinal Study of Ageing” has found that people with poor eyesight are three to five times more likely than those with good eyesight to suffer from low quality of life, poor psychological health, and depression.¹



When those inequalities are accounted for, however, the impact of poor eyesight itself makes almost no difference. By awakening and strengthening other senses that have lain dormant in deference to sight, up to 99% of all normal daily living activities can be continued, and quality of life can be maintained.

A SELF HELP GUIDE TO NON-VISUAL SKILLS

One of the most valuable publications a caregiver can have to help a loved one navigate in a low vision world. Available online or in large print and audio compliments of Prevent Blindness at:

lowvision.preventblindness.org

1 Marmot M, Banks J, Blundell R, Lessof C, Nazroo J. Health, Wealth and Lifestyles of the Older Population in England. The 2002 English Longitudinal Study of Ageing. London: Institute for Fiscal Studies, 2003.

2 “An Examination of Sensory Contributions to Independent Activities of Daily Living” by Dan Roberts (published at www.mdssupport.org/sensory.html, February 2011)

RESOURCES FOR CAREGIVERS

AARP

www.aarp.org/relationships/caregiving

American Red Cross

www.redcross.org

Caregiver.com

www.caregiver.com

Caring.com

www.caring.com

Caring Connections

www.caringinfo.org

CDC Healthy Aging Program

www.cdc.gov/aging

Caring Today

www.caringtoday.com

CNIB publications

www.cnib.ca

eCare Diary

www.ecarediary.com

Eldercare Locator

www.eldercare.gov

Family Caregiving eXtension

www.extension.org

Family Caregiver Alliance

www.caregiver.org

Family Caregiving 101

www.familycaregiving101.org

LTCFocUS.org

ltafocus.org

Medicare Caregiver Info

www.medicare.gov/Caregivers

MySeniorCare

www.myseniorcare.com

National Alliance for Caregiving

www.caregiving.org

National Family Caregivers

www.thefamilycaregiver.org

Network of Care

networkofcare.org

Next Step in Care

www.nextstepincare.org

Rosalyn Carter Institute For Caregiving

rci.gsw.edu

Strength for Caring

www.strengthforcaring.com

This Caring Home

www.thiscaringhome.org

VA Caregiver Support

www.caregiver.va.gov

Video Caregiving

www.videocaregiving.org

Well Spouse Association

www.wellspouse.org