

Contents

	Letter to Readers	iii
	Introduction	v
Chapter One:	Understanding Vision Loss	3
	Eye Conditions	3
	Age-Related Macular Degeneration	4
	Cataracts	6
	Glaucoma	6
	Diabetic Retinopathy	7
	Getting the Diagnosis	8
	Facing Change	9
	The Caregivers' Role in Facing Change	10
Chapter Two:	Adjusting to Vision Loss	13
	Lighting	13
	Doing Things Differently	15
	In the Kitchen	15
	In the Bathroom	16
	Out and About	17
	The Sighted Guide Technique	18
	New Lifestyles and Hobbies	19

Chapter Three:	Low-Vision Aids	23
	Adjusting to Low-Vision Aids	23
Chapter Four:	Caregivers' Checklist	27
	Nurses	27
	Dining Room or Cafeteria Staff	27
	Social Workers	28
	Homemakers, Family, and Friends	28
	Everyone	29
Chapter Five:	Resources	33
	Organizations	33
	The Amsler Grid	35
	Internet Resources	36
	Consumer and Advocacy Groups	36
	Information on Eye Conditions	37
	Information Resources and Services	38
	Guide Dog Resources	39
	Rehabilitation Agencies	39
	Technical Aids Sources	40

Letter to Readers

Dear Readers,

Canada is facing a crisis in vision loss, a crisis related to the aging of a significant portion of the population and the changing demographics of the country. By age 60, one in nine of us will be so visually impaired that daily living activities will be dramatically affected even when using the best prescriptive glasses. By age 80, this figure rises to one in four.

Too often, older people with poor vision accept a greater loss of independence than necessary. Often, simple assistive devices or minor modifications to daily life can reduce the effects of vision loss. With the support of The Canadian National Institute for the Blind (CNIB), vision-care and other health care professionals, family, friends, and peer support groups, considerable independence can still be maintained.

This caregivers' handbook describing conditions of the aging eye and the many simple adjustments that can make up for failing vision was made possible by the Communications and Rehabilitation Departments of the CNIB National Office, and by an education grant from Novartis Ophthalmics.

Please use this handbook as a resource, and remember to call on the CNIB for help when you or someone you know experiences a loss in vision. You don't have to be blind to benefit from the services offered by CNIB centres across Canada. In fact, 90 per cent of CNIB clients have some degree of vision. Also consider, the CNIB was established to help Canadians with poor or failing vision, and 70 per cent of our more than 100,000 clients are over age 60.

Sincerely,

Gerrard Grace

Vice President, Operations and Marketing, CNIB
Vice Chair, AMD Alliance International

“The unselfish effort to bring cheer to others will be the beginning of a happier life for ourselves.”

Helen Keller

This handbook is dedicated to all the selfless caregivers who improve the lives of others by providing care in time of need.

Introduction

One Person’s Experience With Vision Loss: Age-Related Macular Degeneration

by Mary Williams

Age-related macular degeneration (AMD) is a difficult condition to understand, largely because the eyes of a person with AMD look normal. We are still able to manoeuvre around obstacles; we can see a white piece of fluff on a dark carpet and yet we will walk right by a neighbour or best friend without recognizing him.

I recently met with a group of people who have been living with AMD for a number of years. We discussed the impact this condition has had on our lives and soon found that we shared many feelings and experiences.

We want people to understand that we are “visually impaired,” not “slow-witted,” “clumsy,” “standoffish,” or “illiterate.” We sometimes fake “seeing” because it is easier than explaining that we have no central vision. If our companion in the car says, “Just look at that pretty house,” many of us will reply, “Oh yes, how pretty!” rather than explaining, yet again, that we cannot see that kind of detail.

Caregivers need to get as much information as they can about vision loss, and share that information with the people they are caring for and their families. If you are a caregiver to someone with any form of vision loss, we urge you to:

- Become informed; learn as much as you can about the condition.
- Be patient — adjusting to vision loss takes time.
- Connect with a vision rehabilitation agency such as the CNIB (see Chapter Five, page 33).
- Ensure the person you are caring for receives skills training and assessments for adaptive tools.
- Meet other people with the same condition.
- Meet other caregivers.

When I was diagnosed with AMD, it changed not only my own life, but also the lives of my family and friends. I experienced some painful emotions such as disbelief, resentment, anger, and frustration, and often family and caregivers were on the receiving end of those feelings. What really helped me come to terms with vision loss was an increase in confidence and skill level — and that only came with time. Even after years of living with AMD, there are times when those negative emotions return.

Become as informed as you can about the condition of the person receiving care and educate his network of family and friends. Eventually, these steps will help him feel confident, in control, and willing to accept help when needed without feeling dependent on others.

Those of us who contributed to the research and preparation of this handbook believe it will be an invaluable resource. By working together with our caregivers and family members, those of us with AMD or any form of vision loss can live with dignity, confidence, safety, and a strong feeling of self-worth.

Note to caregivers:

The visually impaired person for whom you are caring may be a male or female friend, family member, or someone who has hired you as a professional caregiver. For the sake of simplicity throughout this handbook, we have referred to the person receiving care as “he.”

1

Chapter One: Understanding Vision Loss

Research indicates that people in their 50s have about a two per cent chance of getting AMD. This risk increases to nearly 30 per cent in those over age 75.*

As our population ages, cases of age-related macular degeneration (AMD), glaucoma, and cataracts are on the rise in Canada. For instance, research indicates that people in their 50s have about a two per cent chance of getting AMD. This risk increases to nearly 30 per cent in those over age 75.

Many misconceptions exist about vision loss. For example, very few people who are blind live in a world of total darkness. More than 80 per cent of people who are blind still have some degree of vision. Some can see the outline of objects while others can tell from which direction light is coming. Sometimes, it may be hard to tell if someone is visually impaired at all. As a caregiver, you can maintain the person's dignity and comfort level by remembering the following points:

- Identify yourself and address a person who is blind or visually impaired by name. Let the person know if you are leaving the room.
- Pointing won't help. When giving directions, be specific.
- Describe the surroundings to the person you are caring for each time you are in a new location. Knowing the layout of a room or the view outside the car window will help the person feel comfortable.

Eye Conditions

Each eye condition presents different degrees of vision loss. Here are illustrations of some of the most common:



Macular
Degeneration



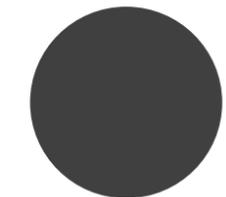
Cataracts



Glaucoma



Diabetic
Retinopathy



Total
Blindness

*Age-Related Macular Degeneration: Principles and Practice. L. Hyman. 1992. Raven Press.

Age-Related Macular Degeneration (AMD)



Age-related macular degeneration (AMD) affects 25 to 30 million people worldwide and is the leading cause of vision loss in Canada.

The macula is located in the centre of the retina, at the back of the eye. It processes the images our brain translates into central vision. The size of a pea, the macula helps us see sharp detail, such as a freckle on a nose.

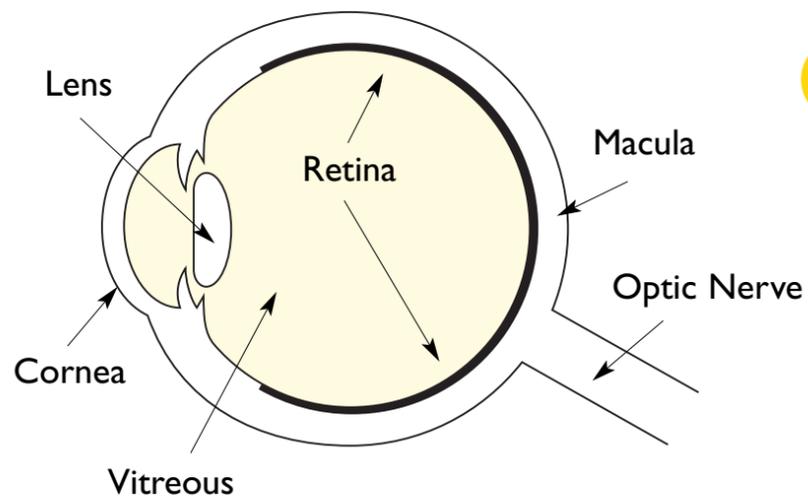


Diagram of the eye

As our eyes get older, the membrane separating the macula from retinal blood vessels can weaken, depriving the macula of nourishment. When the macula degenerates, so does central vision.

AMD can seriously affect one's central vision in just a few months or over the course of several years. In severe cases, scar tissue from leaky blood vessels can cause irreversible blind spots. AMD will never cause total blindness since peripheral vision remains unaffected. For example, people with AMD may see the colour of someone's shirt, but not his face; they might spot a dime on the floor as they walk through a room but cannot read the clock on the wall.



A view through the eyes of a person with AMD.

Photo courtesy of Prevent Blindness America

Even when looking straight at you, a person with AMD will likely be able to see the colour of your hair or if you're wearing a shirt with a collar but will not recognize your face. AMD also makes variations in colour hard to distinguish; for example, someone with AMD may "see" a raspberry-coloured sweater as a soft pink instead. While no two individuals with AMD experience exactly the same degree of vision loss, brighter light and sharp contrast in colour can make objects more visible to anyone with the condition. Ways to improve lighting and colour contrast to help the person's peripheral vision are explained later in this handbook.

There are two forms of AMD: the dry form, which is the most common, and the wet form, which is less common but causes more severe and sudden sight loss. With dry AMD, varying degrees of sight loss are caused by deposits of drusen (age spots) that form in the macula. Wet AMD results from abnormal blood vessels forming and leaking into the macula.

The cause and cure for AMD are unknown. However, treatments are available in a small percentage of cases. Possible risk factors for the condition include smoking, genetics, hypertension, sun exposure, far-sightedness, light skin or eye colour, and poor diet.

Cataracts



A cataract is a clouding of the normally clear and transparent lens of the eye. When a cataract develops, the lens becomes as cloudy as a frosted window, and light cannot be properly focused on the retina, resulting in an unclear image. Often, only a small part of the lens is affected and, if sight is not greatly impaired, there is no need to remove the cataract. If a large portion of the lens becomes cloudy, sight may be partially or completely lost until the cataract is removed.

Depending on the size and location of the cloudy areas in the lens, a person may or may not be aware that a cataract is developing. If the cataract is located on the outer edge of the lens, no change in vision may be noticed, but if it is located near the centre of the lens, it usually interferes with clear sight. As cataracts develop, so may hazy, fuzzy, and blurred vision. Double vision may also occur. The eyes may be more sensitive to light and glare, making night driving difficult. There may also be a need to frequently change eyeglass prescriptions.

Glaucoma



Glaucoma causes the gradual loss of peripheral, or side, vision. Although linked to older age, glaucoma may develop at any age — even infancy.

The cause of glaucoma is unknown, but a number of risk factors have been identified. These include age, heredity, myopia (near-sightedness), increased intraocular pressure (IOP), and systemic disease such as diabetes and hypertension. Vision loss from glaucoma may be caused by increased IOP and other influences on the optic nerve, located at the back of the eye. The diminishing nerve function causes loss of peripheral vision painlessly and without notice.

It is important to be aware of the possibility of glaucoma, particularly if you have any of the risk factors. Some drugs, such as cortisone (steroid) drops, can cause glaucoma. As well, some visual disturbances that cannot be corrected by glasses may be a sign of glaucoma. This is also true for AMD and diabetic retinopathy.

Diabetic Retinopathy



The main cause of visual impairment in people with diabetes is diabetic retinopathy, a condition in which changes occur in the tiny blood vessels that nourish the retina (the light-sensitive tissue that lines the back of the eye and changes the light into nerve messages transmitted to the brain). In the early stages of diabetic retinopathy, small blood vessels weaken and leak fluid or tiny amounts of blood, which distort the retina. At this stage, the person may have normal vision or may experience blurred or changing vision. Although 25 per cent of people with diabetes have some degree of retinopathy, most cases do not progress to more severe problems.

In a more advanced stage, blood vessels in the retina are blocked or closed completely, and areas of the retina die. Proliferative diabetic retinopathy affects about five per cent of people with diabetes and occurs when new, abnormal blood vessels grow to replace the old ones. These new vessels are fragile and often rupture and bleed into the eye, blocking vision. Scar tissue forms, shrinks, and tears the retina, causing bleeding or detachment from the back of the eye. This can result in severe visual loss or blindness. Fortunately, this occurs only in a small minority of people with diabetes.

The chances of having some form of diabetic retinopathy increase the longer a person has had diabetes. Diabetic retinopathy is present in 90 per cent of those who have had diabetes for more than 20 years.

Getting the Diagnosis

Each person will respond differently upon learning they have a serious eye condition. Shock, disbelief, depression, and anger are common reactions — these feelings can last for days, weeks, months, or even years. It can be frustrating for caregivers and family members if a person who is visually impaired or blind has a very negative attitude; however, it is important to remember that a supportive and caring environment is key to successful rehabilitation.



Friendly visits are a great way to show support.

Try not to be overprotective. Sometimes, caregivers, family, and friends can show their concern and support just by “being there.” Friendly visits and organized outings can be of great benefit. Humour is also an effective way to cope with the challenges presented to people who are blind or visually impaired. Though laughter is often the best medicine, don’t use it just to mask a hurtful experience.

Adjustment to any form of vision loss can be a gradual and often emotional process. Here are some ideas to consider as the person receiving care works towards accepting the diagnosis:

- Obtain as much information as you can about the condition of the person you are caring for and how it affects sight. Share the information with the person.
- Find support groups and other resources within the person’s community, such as the CNIB (see Chapter Five, page 33).

- Encourage family and friends to visit and support the person.
- Allow the person you are caring for time to grieve for his lost vision.

Facing Change

Vision loss is one of the many physiological changes people face as they age. When combined with other physically debilitating conditions, they can threaten a person’s self-confidence.



Encourage the person under your care to take charge of her own rehabilitation process.

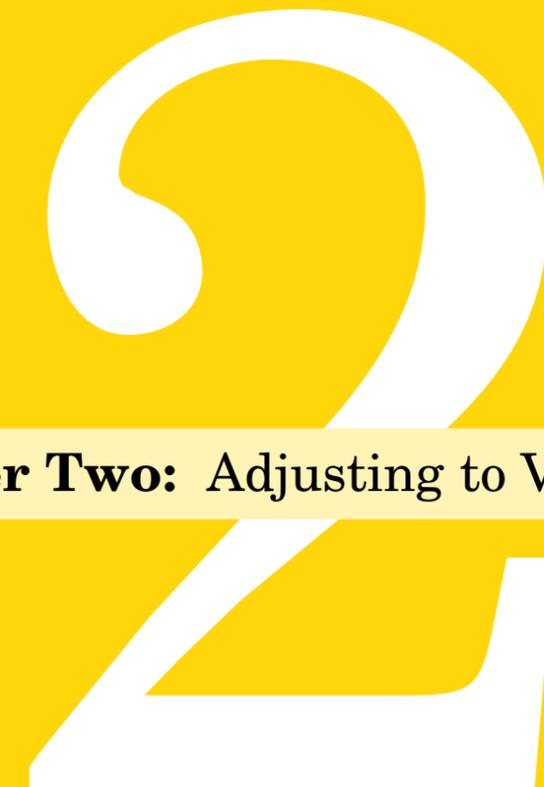
As a caregiver, your role involves empowering and encouraging the person under your care to take charge of his own rehabilitation process — to start working toward that first success that will mean so much.

Later in this handbook we will discuss lifestyle changes that will help maintain the person’s daily living activities. Imagine the sense of accomplishment and pride that a grandmother with AMD will feel once she bakes a batch of cookies for her grandson — thanks to the new adaptive lighting recently installed in her kitchen.

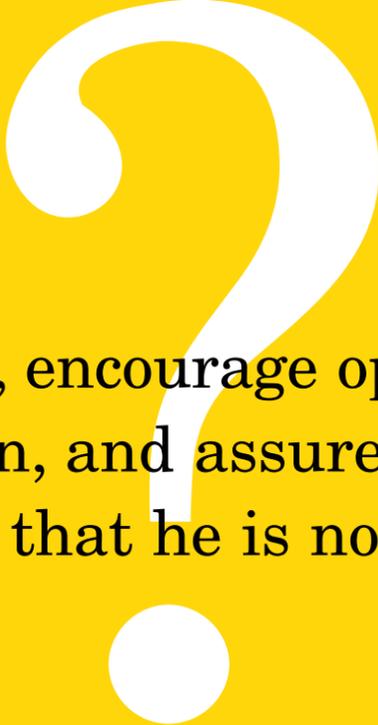
Peer support groups are invaluable. They offer the opportunity to learn how others are coping with their vision loss and how they've learned to do old things in new ways. Vision rehabilitation workers and eye-care professionals can also provide creative solutions to the challenges of living with various eye conditions.

The Caregivers' Role in Facing Change

- Advocate for the person receiving care. Make sure you are both getting the information and services you need. Accompany the person to appointments. Make lists of questions and record the answers.
- Acknowledge that the person may not be a “joiner” and may prefer to talk one-on-one about experiences rather than joining a peer support group. Contact the CNIB to find out more about the counselling services it offers (see Chapter Five, page 33).
- Listen carefully. As the person receiving care adjusts to the loss of vision, he will ask for help only when it's needed. Don't always assume your help is required.
- Ensure the person has access to aids for daily living, such as magnifiers and other items discussed on pages 23 and 24.
- Encourage the person under your care to use his peripheral vision.
- Communicate with family members and especially with other caregivers. Form a support network of your own.



Chapter Two: Adjusting to Vision Loss



As a caregiver, encourage open and honest communication, and assure the person receiving care that he is not a nuisance.

Living with age-related macular degeneration (AMD), glaucoma, cataracts, or any eye condition does not mean that cooking, exercising, socializing, and enjoying a good book become impossible. A few simple adjustments in and around the house will help ensure everyday activities are still within reach.

As a caregiver, you're working in someone's home, whether it is a residence or a short- or long-term care facility. Be sensitive to that fact, and ask the person you are caring for what is needed and what modifications would be most useful. Talk about what you think would be helpful, but always start with what the person identifies as most important.

Sometimes, people with vision loss find it hard to ask for help, for fear of being a nuisance. Tasks that once required no thought, such as hanging a picture, now require the help of a friend or caregiver. Offer to help as often as you think is appropriate, but be specific. Instead of an open-ended offer such as "Let me know if you need anything," say, "I am driving to the store. Would you like to come?" As a caregiver, encourage open and honest communication, and assure the person receiving care that he is not a nuisance.

Lighting

Both inside and out, brighter and strategically placed lighting will make a world of difference to a person living with vision loss. As we age, we require much more light than younger people. People with vision loss, especially seniors, find that they need even more light than their sighted peers. Extra lamps throughout the home provide increased lighting and will help someone with vision loss make the most of his remaining vision. A brighter home is also safer.

Consider the type of light bulb used. Different types of light bulbs create different kinds of lighting. Incandescent bulbs are cheap and easy to find. However, they give off a yellow glow that is not ideal for some people with vision loss. Modern fluorescent lights consume less

electricity and do not radiate much heat, but some may find they cause too much glare. Halogen bulbs are often used in today's fashionable lamps and provide wonderful task lighting, using very little electricity. However, because they do give off a great deal of heat, many people with or without vision loss find halogen lights difficult to use for long periods of time.

Offer to visit a lighting store with the person receiving care. Let a salesperson show you the differences between various forms of lighting. Bring a newspaper or book to help determine which type of bulb is best.

Sensor lights are a relatively inexpensive way to make sure the home's exterior entrance is always lit. Install lighting inside closets, cupboards, in staircases, or even in the shower (be sure to use a waterproof light). Most important, however, is the addition of bright task lighting throughout the house. Task lighting can be aimed directly at what needs to be illuminated, whether the person under your care is writing, sewing, or reading. Small clip-on lights are suitable, as are bendable gooseneck lamps. Buy a tiny flashlight or penlight to be carried at all times. It will come in handy more often than you may imagine, especially in dim restaurants or when unlocking the front door at night.

Reduce glare whenever possible. Window accessories such as sheers or shades will help keep glare out of rooms. Make sure the person receiving care has a hat with a visor for visits to stores that use glaring fluorescent lighting. An eye-care professional can help select a pair of tinted anti-glare sunglasses for outdoors that will eliminate glare from the sides and top, which is far better than the protection regular sunglasses provide.

Doing Things Differently

In the Kitchen

Countertops can be painted to contrast with dishes, cookware, and other items. Any paint or hardware store can tell you which products would be appropriate for painting a countertop. Here are some other tips on how to make the kitchen easier to use and safer for someone with vision loss.

Kitchen Checklist:

- Paint or replace electrical outlet covers in a colour that contrasts with the wall.
- Instead of painting, outline counter edges and electrical outlets with wide tape of a contrasting colour.
- If the stove surface is a light colour, consider replacing stainless steel pots and pans with dark-coloured ones.
- Use light-coloured dishes on a dark tablecloth, or vice versa.
- Mark frequently used settings on the oven or other dials with a thick swipe of bright nail polish.
- Relabel jars and canned goods using a thick black marker and index cards, which can be reused.
- Remove small throw rugs from the kitchen — they are not easily seen and may be a tripping hazard.
- Keep cupboard doors and drawers closed at all times, and make sure that everything is always put away in its proper place.



The large-print labels on these canisters can make cooking much easier.

- Use the “clock method” to identify where certain foods are located on a plate. For example, “The rice is at three o’clock, and the beans at seven o’clock.”



The “clock method” makes locating food on a plate easy.

In the Bathroom

Rehabilitation specialists from The Canadian National Institute for the Blind (CNIB) are excellent resources for caregivers, as they can recommend many techniques that will help people with vision loss maintain privacy and independence in the bathroom.

Here are some tips to make the bathroom as safe as possible.

Bathroom Checklist:

- Use illuminated and magnifying mirrors.
- Use a coloured toothpaste so it shows more on the white bristles of a toothbrush.
- Use towels that contrast in colour with the bathroom décor.
- Use a rubber-backed mat in the tub.
- Float a brightly coloured sponge while running the bath water. The sponge will indicate how high the water has risen.
- Throw out old medication.

- Label current medication with a thick black letter on each bottle; keep a large print list in the medicine cabinet explaining what is what, e.g., “A: blood pressure pills. Take one each morning.”
- Pick up the bath mat after each use and fold it over the edge of the tub to prevent tripping.

Out and About

Now that you’ve made some changes in the home, take a look at how to make things easier outdoors. Careful planning and good organization will help, whether or not you accompany the person under your care on an outing.

Proper training from someone qualified in independent travel skills will help the person feel more confident about venturing outside the home. Some people with low vision find a white cane to be very helpful, not just for getting around, but also for identifying to others that they have a visual impairment that may not otherwise be obvious. There are different varieties of white canes to suit the needs of different users, including collapsible travel canes, white support canes, and long travel canes. While some people are not comfortable using a white cane, most realize that the advantages outweigh the disadvantages, and use the white cane as a mobility tool and identifier. If you think the person receiving care would appreciate a white cane, contact your local CNIB service centre (see Chapter Five, page 33).



The white cane is an important tool that can help maintain independence.

The Sighted-Guide Technique

If you are acting as a sighted guide, walk half a step ahead of the person under your care. Let the person lightly grasp your arm just above the elbow. Approach curbs, stairs, and doorways squarely — never at an angle, and let the person know when to step up or down. Come to a full stop before stairs; if necessary, switch sides so the person can use the handrail. The person will find the first step by sliding his foot forward until he feels the stair, and you will proceed up or down together. Always remain half a step ahead of the person you are guiding and announce when you've come to the last step.



Walk with the person under your care grasping your arm above the elbow.

If the person receiving care is travelling alone, he will rely on peripheral or remaining vision, hearing, or the white cane to provide guidance.

As with any activity, confidence and skill come with time. Chapter Three, on page 23, discusses a number of low-vision aids such as telescopes that can be used to identify street signs and addresses. Some people who are blind or visually impaired will be more open to the idea of independent travel than others. As a caregiver, be sensitive to the wishes of the person receiving care. You may find that after a period of adjustment, the person has come to terms with vision loss and is now more willing to run errands without your help.

Here are some ways for the person under your care to manage potentially frustrating situations outside the home.

Independent Travel Checklist:

- Use large-print cheques and writing guides to make signing easier.
- Identify coins by touch and fold paper money or separate it in the wallet by denomination.
- Take a moment to let the eyes adjust when switching from a bright environment to a dimly lit one.
- Carry a magnifier and/or penlight to read labels, price tags, elevator buttons, or directions.
- Use a mini tape recorder to make a shopping list, instead of struggling with a handwritten list.
- Tell the bus driver in advance which stop you require, and sit at the front of the bus.



Carry a magnifier or penlight to read labels.

New Lifestyles and Hobbies

Meeting people and joining social groups can be challenging for someone with low vision. Making eye contact is usually the first thing people do. But for people with vision loss, this is not always possible. Many people with vision loss avoid social interaction for this reason. Arrange for a friend or peer to accompany the person and help make the initial introductions. Explain to the person's friends that their smiles and waves can't be seen. Encourage others to identify themselves to the person receiving care. For example, "Hi, Lesley. It's Sandra. How are you doing?"

Driving is one activity that people with severe vision loss find extremely hard to give up. However, activities such as reading or playing a musical instrument can continue with a little patience and adjustment. For instance, large-print books or a magnifier may help with reading. Sheet music can be enlarged using a photocopier. Braille music scores are also available.

Family members, friends, and caregivers can play a lead role in identifying new hobbies that require less vision. Talking books, for example, are an excellent substitute when reading becomes too difficult. Audio and large-print books are available from many sources such as libraries and bookstores.

Large-print crossword puzzles and playing cards are available for those who enjoy these activities as part of their daily routine. Sports enthusiasts can also rethink the way they normally exercise; the person under your care can take a walk with a friend instead of alone, or use the schoolyard track for longer distance exercise. Stationary bikes and other seated equipment in most gyms and fitness clubs are also an excellent way of staying active.



People with vision loss may enjoy large-print playing cards.

Changing one's lifestyle is difficult and requires flexibility and patience, from both the caregiver and the person receiving care. A lifetime of pleasures and pastimes is hard to let go of; however, clinging to old hobbies can sometimes lead to frustration and, ultimately, less enjoyment. As a caregiver, encourage a move towards productivity. Be creative. The impact of vision loss may be a chance to make some very exciting changes in the life of the person receiving care.

Chapter Three: Low-Vision Aids



Using one's remaining vision will not cause further deterioration of an eye condition; it will train the brain to interpret images more easily.

People who are blind or visually impaired do not need to stop going to movies or give up their weekly card game. A variety of easy-to-use low-vision aids, including large-print or braille playing cards, can be purchased at vision rehabilitation assistive devices stores, drugstores, eyewear outlets, and specialty stores across the country. Using one's remaining vision will not cause further deterioration of an eye condition; it will train the brain to interpret images more easily.

Low-vision aids make images appear larger, clearer, and easier to see. Magnifiers are among the most useful low-vision aids and come in pocket-size, stand-mounted, handheld, and illuminated models. Many people with low vision find that they need a few different magnifiers — one for fine detail tasks, one for watching television, and one for reading street signs (like a telescopic device that makes distant objects appear closer). Magnification technology is constantly being updated, and new products continually appear on the market.

In fact, gift buying is now much easier for the family and friends of the person receiving care. For example, instead of receiving yet another scarf, tablecloth, or sweater, you can make a list of low-vision devices that would be greatly appreciated. Large-print cookbooks, audio books, portable audio recorders, or a phone with extra large buttons are ideal gifts for a loved one who is experiencing vision loss.

Adjusting to Low-Vision Aids

Encourage the person you are caring for to be patient. It takes time and practice to master the use of any new piece of equipment. Make sure that the low-vision aid is being used properly to maximize its effectiveness. For example, it can be very dangerous to walk to the store while wearing reading glasses. And finally, remember to investigate other higher technology products that are available, such as home computers. If a computer is available, encourage the person to use e-mail instead of handwritten letters to keep in touch with friends and family. The font size on a computer screen can be

enlarged to make the print easier to read. More people are online than ever before and use the Internet to search for recipes, maps, and other information that can be enlarged on the screen.



CCTVs can magnify objects up to 40 times.

Closed circuit televisions (CCTVs) can be very useful to people with low vision. A CCTV consists of a camera and a screen monitor. An object is placed under the camera, magnified (some provide up to 40 times magnification), and displayed on the monitor. This is an excellent way to read labels on prescriptions, read the newspaper, or write cheques.



Large-print telephones make dialing easier.



A handheld magnifier has unlimited uses.

If the person you are caring for can no longer read large-print, learning braille is also an option. For more information on learning braille, contact the CNIB (see Chapter Five, page 33).

4

Chapter Four: Caregivers' Checklist



The main objective for all caregivers is to help maintain the independence and dignity of the person receiving care.

The following checklists will be of great value to you as a caregiver, whether you are a family member, friend, or trained professional. Whether you are involved on a daily or occasional basis, these lists will help ensure that the person under your care enjoys a healthy and independent lifestyle.

Nurses:

- Ensure that the person under your care has annual low-vision assessments to catch any change in vision.
- Be sure you have a clear understanding of the person's eye condition in terms of functionality, not just pathology.
- Ensure that the person has a thorough understanding of his eye condition and any required medication.
- Determine how well the person is using any remaining vision. A specialist at a low-vision clinic can suggest helpful optical aids.
- Be aware of other physical or age-related conditions related to the person's vision loss.

Dining Room or Cafeteria Staff:

- Use the "clock method" to describe the location of food on a plate (see page 16).
- Use a colour of table linen that contrasts with the colour of the place setting.
- Ensure that there is staff available to help the person get to the table or cut food.
- Show the person how to shake salt and pepper into his palm before sprinkling it on food. This will prevent fast-flowing shakers from ruining meals.
- Describe the colour, flavour, and texture of the food when explaining food selections.

Social Workers:

- If the person receiving care is hesitant to socialize because he cannot make eye contact or may not know who else is in a room, arrange for a friend or peer to accompany him and help make the initial introductions.
- Explain to the person's friends that their smiles and waves can't be seen.
- Encourage others to identify themselves to the person receiving care. For example, "Hi, Mary. It's Nancy here to meet with you."

Homemakers, Family, and Friends:



Let the person receiving care decide how things should be labelled.

- Remember to put things away exactly as you found them.
- Let the person receiving care (or friend or relative) help you decide how things should be organized, labelled, or adapted in the home.
- Help the person explore new hobbies, interests, or activities to replace those that require better eyesight.
- Anticipate obstacles and make adjustments before an accident occurs.

- If asked, read personal or business correspondence discreetly and out of earshot of others. Always maintain confidentiality when assisting with such tasks.
- Encourage the person you are caring for to perform many tasks as independently as possible.

Everyone:

- Be aware of your own emotional reactions to vision loss or blindness, so that you will not be overwhelmed when your assistance is needed.
- Use specific, positive wording when you offer to help. For example, "I shop on Tuesday mornings. Would you like to come with me?" rather than "Let me know if you want to go shopping."
- Clear your home of obstacles such as empty boxes, shopping bags, throw rugs, snow, or ice, and be sure areas are well lit.
- Let the person receiving care know when you are leaving the room and when someone has entered.



Encourage the person receiving care to explore new hobbies.

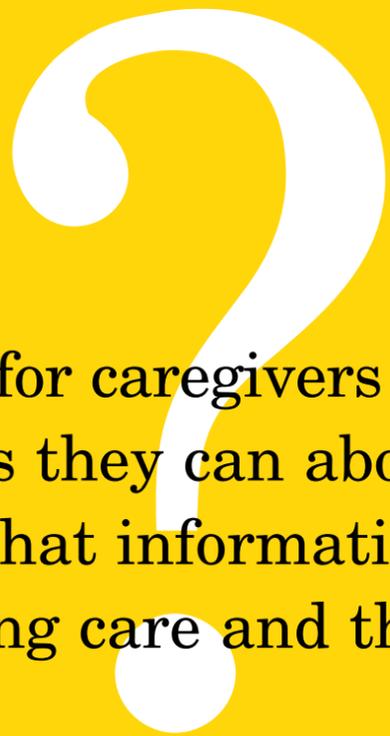
Don't make assumptions about the impact of diminishing or low vision. And remember that, although visual impairment can be harder for many sighted people to understand than total blindness, having to explain their situation over and over again can be very frustrating for people with visual impairments.

The main objective for all caregivers is to help the person receiving care maintain independence and dignity. No two people, whether blind, visually impaired, or sighted, function the same way. Therefore, no two people require the exact same help. The best question to ask yourself is, "What can I do to help?"



Encourage the person under your care to perform many tasks as independently as possible.

Chapter Five: Resources



It is essential for caregivers to get as much information as they can about vision loss and to share that information with the people receiving care and their families.

Organizations

AMD Alliance International

1314 Bedford Ave., Ste. 210

Baltimore, MD 21208

U.S.A.

Toll-Free Hotline: U.S./Canada:

1-877-AMD-7171

(1-877-263-7171)

www.amdalliance.org

The Canadian Association of Optometrists

234 Argyle Ave.

Ottawa, Ontario

K2P 1B9

1-888-263-4676

www.opto.ca

The Canadian National Institute for the Blind

National Office

1929 Bayview Ave.

Toronto, Ontario

M4G 3E8

1-800-513-7813

www.cnib.ca

Canadian Ophthalmological Society

610-1525 Carling Ave.

Ottawa, Ontario

K1Z 8R9

(613) 729-6779

www.eyesite.ca

The Foundation Fighting Blindness — Canada

60 St. Clair Ave. E., Ste. 703

Toronto, Ontario

M4T 1N5

1-800-461-3331

www.ffb.ca

International Federation on Ageing (IFA)

425 Viger Ave. W.

Montreal, Quebec

H2Z 1X2

(514) 396-3358

www.ifa-fiv.org

National Coalition for Vision Health

1929 Bayview Ave.

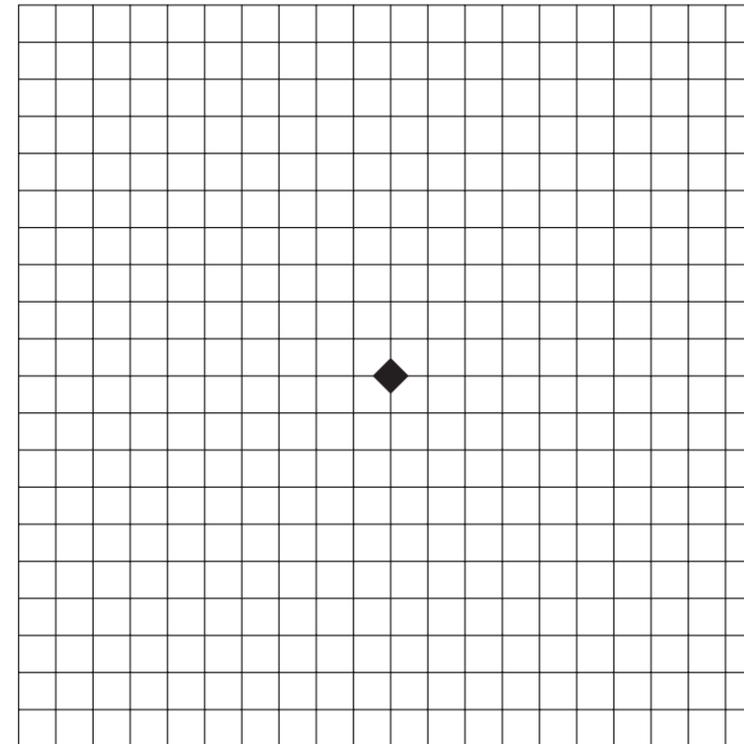
Toronto, Ontario

M4G 3E8

(416) 480-7687

www.visionhealth.ca

The Amsler Grid



The Amsler Grid is a chart that may be helpful in revealing signs of wet AMD; however, it is not a substitute for regularly scheduled eye exams, which should take place at least once every two years, especially after the age of 40.

To administer the test, hold the Amsler Grid at eye level at a comfortable reading distance. If you wear any type of reading glasses, wear them during the test. Cover one eye at a time, and focus on the centre dot. If you notice any of the potential signs of AMD such as wavy, broken, or distorted lines or blurred or missing areas of vision, you should contact your eye-care professional immediately.

Internet Resources

The following list of Web sites is a sample of useful information resources. For additional Web sites, search under the keywords “eye conditions” and “low vision.” The reader is reminded that Internet Web addresses change from time to time.

Consumer and Advocacy Groups

www.alcoa.ca

Active Living Coalition for Older Adults

www.50plus.com

Canadian Association of Retired Persons

www.ccc-ccan.ca

Canadian Caregiver Coalition

www.ccbnational.net

Canadian Council of the Blind

www.cnsdb.ca

Canadian National Society of the Deaf-Blind

www.clickintocaregivers.com

Click-Into Caregivers

www.ifa-fiv.org

International Federation on Ageing

www.visionhealth.ca

The National Coalition for Vision Health

www.nfbae.ca

National Federation of the Blind: Advocates for Equality

Information on Eye Conditions

www.amdalliance.org

AMD Alliance International

www.opto.ca

Canadian Association of Optometrists

www.cdbra.ca

The Canadian Deafblind and Rubella Association

www.diabetes.ca

Canadian Diabetes Association

www.eyesite.ca

Canadian Ophthalmological Society

www.cataractcanada.com

Cataract Canada

www.ffb.ca

Foundation Fighting Blindness

www.glaucoma.org

Glaucoma Research Foundation

www.hc-sc.gc.ca

Health Canada (search under “diseases” and “conditions”)

www.helenkeller.org

Helen Keller Services for the Blind

www.macula.org

Macula.org

www.nei.nih.gov

National Eye Institute of the National Institutes of Health

www.tr.wou.edu/dblink/links.htm
National Information Clearinghouse on Children Who Are Deaf-Blind

www.novartisophthalmics.ca
Novartis Pharmaceuticals Canada Inc.

www.visionsimulator.com
Pharmacia Corporation

www.kellogg.umich.edu
University of Michigan W.K. Kellogg Eye Center

www.eyeinstitute.net
University of Ottawa Eye Institute

Information Resources and Services

www.ccr-aadrc.gc.ca
Canada Customs and Revenue Agency

www.canada411.sympatico.ca
Canada 411

www.deafblind.com/canada
Canadian Organizations for Deafblind People

www.voiceprint.ca
National Broadcast Reading Service

www.nlc-bnc.ca
National Library of Canada

Guide Dog Resources

www.guidedogs.ca
Canadian Guide Dogs for the Blind

www.dogguides.com
Lions Foundation of Canada Guide Dogs

www.mira.ca
Mira Foundation

Rehabilitation Agencies

www.afb.org
American Foundation for the Blind

www.cnib.ca
The Canadian National Institute for the Blind

www.inlb.qc.ca
Institute Nazareth et Louis-Braille

www.surdite.org/ird.htm
Institute Raymond-Dewar (This site is in French.)

www.lighthouse.org
Lighthouse International

www.mab.ca
Montreal Association for the Blind

