<table>
<thead>
<tr>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>About the Author</td>
<td>3</td>
</tr>
<tr>
<td>I’m Visually Impaired, But —</td>
<td>4</td>
</tr>
<tr>
<td>20 Things Eye Doctors Probably Don’t Tell You (But Would Like You To Know)</td>
<td>6</td>
</tr>
<tr>
<td>Catching The Big One</td>
<td>13</td>
</tr>
<tr>
<td>Correcting Misconceptions About AMD</td>
<td>15</td>
</tr>
<tr>
<td>Detours</td>
<td>21</td>
</tr>
<tr>
<td>Every Patient Can be an Advocate</td>
<td>22</td>
</tr>
<tr>
<td>Former Driver, Retired With Honor</td>
<td>25</td>
</tr>
<tr>
<td>Hidden Disabilities: A Social Dilemma</td>
<td>26</td>
</tr>
<tr>
<td>Hidden Thoughts of the Visually Impaired</td>
<td>30</td>
</tr>
<tr>
<td>How Cope-able Are You?</td>
<td>35</td>
</tr>
<tr>
<td>I Can't See What You Mean</td>
<td>37</td>
</tr>
<tr>
<td>I Can't See What You're Saying</td>
<td>39</td>
</tr>
<tr>
<td>Is Blindness The &quot;Worst Ailment&quot;?</td>
<td>40</td>
</tr>
<tr>
<td>Is Brittany Blind?</td>
<td>41</td>
</tr>
<tr>
<td>Learning to Live with Low Vision: One Man’s Journey Through</td>
<td>49</td>
</tr>
<tr>
<td>Rehabilitation (Jim’s Story)</td>
<td></td>
</tr>
<tr>
<td>Loss of Confidence</td>
<td>64</td>
</tr>
<tr>
<td>Musings on Growing Old</td>
<td>67</td>
</tr>
<tr>
<td>The Monster Behind The Door</td>
<td>69</td>
</tr>
<tr>
<td>“The T.A.S.K. of Living With Central Vision Loss”</td>
<td>74</td>
</tr>
<tr>
<td>What Can I Do To Keep Busy?</td>
<td>87</td>
</tr>
<tr>
<td>What’s So Funny About Low Vision?</td>
<td>90</td>
</tr>
<tr>
<td>A Blouse For Church (Edna’s Story)</td>
<td>99</td>
</tr>
<tr>
<td>Getting My Mail (Susan’s Story)</td>
<td>100</td>
</tr>
<tr>
<td>A Blurry Night Before Christmas</td>
<td>101</td>
</tr>
<tr>
<td>A Miracle</td>
<td>102</td>
</tr>
<tr>
<td>A Parable of Vision</td>
<td>103</td>
</tr>
<tr>
<td>I See</td>
<td>105</td>
</tr>
<tr>
<td>The Promise</td>
<td>106</td>
</tr>
</tbody>
</table>
About the Author

Dan Roberts is Editor-in-Chief with Prevent Blindness, Founding Director of Macular Degeneration Support, Resource Director for Macular Degeneration Foundation, and Founding Director of the International Low Vision Support Group.

Having retired from a half century as a teacher, author, composer, theatrical director, and musician, Dan dedicated himself in 1995 to helping others learn about and live with low vision. Because of his personal need for support and information about visual impairment, he founded MD Support and has since become a leading patient advocate, lobbyist, industry consultant/advisor, and low vision educator.

Dan is the author of *The First Year–Age-Related Macular Degeneration* (Marlowe & Co., New York, NY, 2006) and contributing author to *Occupational Therapy Intervention for the Older Adult With Low Vision* (American Occupational Therapist Association, 2010), plus several booklets on various subjects of interest to the low vision community. *Living Well With Low Vision* is a compilation of his 100+ shorter writings during his more than 25 years of service.

He is a graduate of the University of Missouri with a master’s degree in music education. He is the recipient of the 2004 Distinguished Service Award presented by the American Optometric Association, and his flagship organization was honored with the National Eye Institute’s 2006 Healthy Vision Community Award for innovative approaches to vision-related health education.

Dan married Christina in 1968 while serving in the U.S. Air Force. They have three children, seven grandchildren, and one great grandchild.
I’m Visually Impaired, But . . .

As we age, we face a number of challenges not enjoyed by the young. It seems like every day brings another condition that makes us wonder, “Is this the Big One that’s going to do me in?”

Fortunately, most of these conditions are temporary, rearing their heads only to warn us that we’re not as young as we used to be. Maybe that extra cupcake was not a good idea. Maybe that extra step up the ladder wasn’t worth wearing an ace bandage the rest of the summer. Maybe if I had a better way of sorting my mail, I would have remembered to pay that water bill.

But unfortunately, some ailments don’t go away. Age can bring on vision and hearing loss, memory decline, osteoporosis, arthritis, incontinence, diabetes, and any number of other nasty annoyances to make us miserable. And the older we get, the more they pile up, until we start thinking that maybe old man Job didn’t have it so bad after all.

That’s when we need to boost our morale by putting things into perspective. We can start by reminding ourselves of specialties we have developed, or hope to develop, that can give us the confidence to continue down a road filled with obstacles. In other words, what specialities do we have that can balance the negatives? That question can be answered by completing this thought:

“I have [a condition that’s tough to deal with], but . . .”

Below are responses by people from the MD Support community who were asked to finish the sentence as it relates to their vision. We encourage you to make your own list, and then allow your specialties (you know you have them) to balance, or even outweigh, the challenges in your life. With how many of these can you identify?

“I’m visually impaired. but . . .
. . . it doesn’t define me.”
. . . I’m very thankful for the good things I have.”
. . . I’m a trouper!”
. . . I have a strong and determined mind.”
. . . it’s just one part of my life, and I’m getting on with it.”
. . . I’m a good planner.”
. . . I know how to adapt.”
. . . I keep up on assistive technology.”
. . . I’m persistent.”
. . . I’m otherwise healthy.”
... I'm financially secure enough to take care of myself.”
... I'm proactive.”
... I don’t hesitate to ask for help.”
... I believe in myself.”
... I have a full life.”
... I have supportive friends and family.”
... I'm anxious to learn new ways to do things.”
... I can dance.”
... I make things happen.”
... I've found that living in the world of books is a good replacement for people no longer around.”
... I believe in dreams.”
... I believe in a higher power.”
... I still have my sense of humor.”
... I have employment skills.”
... I keep busy volunteering.”
... I'm working through it and overcoming the fear.”
... I have confidence in the future.”
... I’m trying every day to adjust to the new norm.”
... I continue to learn how to help others.”
... I continue to learn how to help myself.”

How many more can you add?


20 Things Eye Doctors Probably Don’t Tell You (But Would Like You To Know)

Optometrists and ophthalmologists are human. And like the rest of us humans, they can get tired, impatient, frustrated, despondent, and hurt. Unfortunately, professional decorum requires that they maintain a good front by either bottling up their thoughts or venting them at home, neither of which are necessarily good options.

For that reason, I have gathered comments heard behind the scenes from doctors with whom I have been privileged to associate over the past 20 years. This may not speak for all of them, but I do think it is representative of the majority.

So here are 20 private thoughts of doctor which, like them or not, we might benefit from hearing.

1. Private thought:
   “You’re no spring chicken.”

Translation:
   “Your sight cells are growing older, and I can’t turn back the years in an aging retina. I can, however, help you try to maintain your current vision for as long as possible.”

2. Private thought:
   “You’re welcome . . . Just in case you were about to thank me and got sidetracked.”

Translation:
   “Your appreciation means a lot. Don’t hesitate to compliment me if I have earned it.”

3. Private thought:
   “I’m going to buy a parrot.”

Translation:
   “I don’t have time to repeat myself, so if it helps, please take notes, or bring someone with you who can refresh your memory later.”

4. Private thought:
   “And where have YOU been for the past two years?”
Translation:
“It is important that you do your homework and comply with my instructions. If you don’t show up for appointments, or wear your sunglasses, or you cheat on your medications, nutrition, or exercise, I cannot be responsible for your outcome. Showing up on time for your appointments is also important. Remember, you and I are partners in your care, and we each have to row our side of the boat.”

5. Private thought:
“*What do you want from me?*”

Translation:
“I’m an eye doctor. As much as I might like to also be your rehabilitation specialist, counselor, minister, financial adviser, benefactor, teacher, and psychologist, I just don’t have the time or training to be all of those things. I will, however, try to provide you with resources for any shoes I cannot fill.”

6. Private thought:
“*What does your cousin Rita’s lumbago have to do with your test results?*”

Translation:
“During your visit, please be concise with your questions and stay on topic so I’ll have time to treat other deserving patients. And please don’t wait until the end of your appointment to start asking questions. If you let me know at the beginning that you have questions, I’ll save time for them.”

7. Private thought:
“*No, sleeping with pickles on your eyelids will not improve your sight. Where on Earth did you hear that?*”

Translation:
“Don’t believe what you see in the media unless the source is reliable. If the information isn’t based on scientific proof, or at least good evidence, my response to you may be disappointingly negative.”

“To check the source yourself, look for footnotes or other references to publication in professional journals. Then check to see if the source has a commercial interest. That can be done easily by searching with key words on the Internet. If you find that there has been no peer-reviewed study, or
that the information is coming from a source that stands to profit, or if it simply sounds too good to be true, be skeptical.

“Or go ahead and ask me about the pickles, but please forgive me if I roll my eyes a little.”

8. Private thought:
   “Is that how you treat someone who sends you birthday cards?”

Translation:
“If I refer you to another doctor for a second opinion, and that doctor confirms my diagnosis, I hope I will see you in my office again, because I don’t want to lose you. I encourage you to double-check my findings; and if the second doctor doesn’t agree with me, you might want to get a third opinion. But at some point, you will need to make a decision. Unfortunately, patients are sometimes caught in the middle and have to make the decision on which doctor to work with and what treatment to get.”

9. Private thought:
   “I would answer your question, but I would have to inhale.”

Translation:
“Please take care of your personal hygiene before your appointment. We have to work in close proximity, so a morning shower, fresh breath, and little or no perfume are much appreciated. And I promise to do the same!”

10. Private thought:
    “Do I look like Nelson Rockefeller?”

Translation:
“I may appear rich, but I have so many expenses and debts resulting from my profession that my bottom line after taxes is probably not much different than yours. Here is where my money goes:

• Clinic space rent, utilities, and maintenance
• Staff salaries and benefits
• Malpractice insurance for me and my staff
• Purchase and maintenance of diagnostic and surgical equipment
• Student loan payments for up to 12 years of college
• Continuing medical education
• Professional conference fees and expenses
• Society membership dues
• Subscriptions to professional journals
“I am in private practice, while other doctors work under salary. Some of these expenses may, therefore, will be different, but we all have one thing in common. That is, the pressure of maximizing our patient load.

“95% of my patients are insured by Medicare or companies that establish their premiums based upon Medicare rates. As a result, I get only about 60% of what I charge insured patients. Many uninsured patients can’t afford to pay at all, and those I just have to write off as a loss.

“I’m not complaining, mind you. Okay, maybe I am a little. But the positives of what I get to do for a living far outweigh the negatives. I may not be rich, but I’m definitely ENriched, and that’s what counts.”

11. Private thought:
   **You get what you pay for.”**

Translation:
   “I do not choose a particular drug or treatment by how much I might make from it. I can ask up to 6% over my cost for a Medicare-approved drug, but that helps keep my treatment costs reasonable. And speaking of treatment costs, I base my fees on four factors:
   1. The extent of my training, knowledge, and experience
   2. The going rate for such services
   3. The economy of the community
   4. My business expenses
   “I have to be both a doctor and a business person. My obligation is keeping the eyes of several hundred people healthy; but equally as important is my obligation to provide for my family. To do both of those things well, I must charge each of my patients enough to stay in practice.”

12. Private thought:
   **“I’m not out to get you.”**

Translation:
   “You might hurt my pride or make me angry, but rest assured that I will never seek revenge by purposely providing you with poor care. Not only could that be grounds for a malpractice lawsuit, but such behavior would violate my personal ethics and my pledge to ‘do no harm’.”

13. Private thought:
   **“I know your name, but I can’t place your face.”**
Translation:
“I may not remember you personally, especially in the beginning or if I see you only once or twice a year. Your records, however, will contain everything I need to know to care for your vision.”

14. Private thought:
“Ummm…”

Translation:
“Don’t expect me to keep all of the research in my head. But I do know where to look it up, so allow me some time to get back to you on that important question. And along that same line, if a commercial for a new drug advises you to “ask your doctor”, please give me a reasonable period of time to look into it before offering my opinion. Sometimes the market changes faster than I am able to keep up.

“And just a little side note: Please don’t offer a diagnosis or treatment for your condition. Just clearly identify your symptoms, and let me earn my pay.”

15. Private thought:
“If I tell you I’ll be out of the office next week, you’re going to give me that “I’m going blind, and you’re off to the beach again” attitude again, aren’t you?”

Translation:
“Yes, those conferences I attend are sometimes in exotic places, but most of the time is spent going from one exhibit, research presentation, or workshop to another, with little or no time left for sunning on the sand. I go to learn and share ideas, and that’s time well spent for both of us.”

16. Private thought:
“Why would I use up precious clinic time just so you can pay me to tell you you’re no better?”

Translation:
“Even if there is no effective treatment for your disease, you still need me to see you regularly to monitor your condition. It may appear that I’m just lining my pockets, but just because you have the measles doesn’t mean you can’t get the mumps. Regular check-ups are important to your health and preventative care.”
17. Private thought:
   “There’s a million-to-one chance of a patient losing vision with this treatment, and guess who sits in my chair whose cousin is an ambulance-chasing attorney?”

Translation:
   “Unexpected side effects and adverse events are beyond a doctor’s control. I understand that it doesn’t matter if the odds are one in 10 or one in a million…if you are the “one”. Our decisions and chosen treatment protocols may not always be 100% spot on, but please know that, as for me, I will always do my best to keep you healthy and safe. And, if that is ever in doubt, I will be happy to refer you to someone for a second opinion.”

18. Private thought:
   “I’m not a miracle worker.”

Translation:
   “I regret that miracles are above and beyond my capabilities right now. If your disease is chronic, I may not be able to cure you. Sometimes, all I can do is help your vision last as long as possible.”

19. Private thought:
   “You’re going to attach WHAT to your eyeballs?!”

Translation:
   “I may not agree with your decision to try an untested alternative treatment, but I respect your right to do so. All I ask is that you seriously consider my opinion, and if you decide to go ahead with the treatment on your own, please keep me in the loop so I can monitor your condition.”

20. Private thought:
   “I’m not a candy man.”

Translation:
   “If I give you free samples of supplements or medications provided to me by manufacturers, I do not do so for promotional purposes. I may be associated with a company as an advisor or consultant, but I am not bound to them commercially. And you might be surprised to know that I probably don’t even know the over-the-counter price of some of the samples I give you. If you ask me about alternative brands or generics, I will give you an honest, unbiased response.”
We should do our best to understand the professionals who care for us. They, in turn should provide us with as many resources as we require to understand our disease and treatment. Our cars and appliances come with maintenance manuals and technical support. We should expect no less from our doctors. And it doesn’t have to take time out of the examination. Videos and informational literature can be dispensed by the receptionist or be made available in the waiting room. Of course, the doctor would want to initially preview and select such material, but that would be time well invested.

So the next time you visit your doctor, and you pick up on a slight change in demeanor, or a little role of the eyeballs, or maybe a glint of humor, it may be a good time to take a look at the doctor’s side of things. Doing so could turn a top-down doctor-patient relationship into one of mutual respect and understanding. You might even find that you get a few extra minutes of precious time, just because you’re a pleasure to have around.
Catching The Big One

When Harold was twelve, he rarely thought about The Big One. He would leap from high places, race his Schwinn over steep ramps, play with fire, and defy The Big One with all other manner of bravado.

Then, one especially exuberant day, sporting a Superman cape made from his mother’s Christmas table cloth, Harold flew blindly into the gravel road by his house. Five hours later, Superman awoke in a hospital bed, bruised, but unbroken, which he credited to his super powers.

Doc Flanders said he was lucky he didn’t catch The Big One. That sounded like a good thing, but Harold wasn’t sure what he meant. “You gotta be more careful, boy. If the truck driver hadn’t seen your red cape, it could have been the death of you.”

Oh. That Big One.

Harold’s dad had briefly discussed the meaning of death a few years earlier when he said, “Your hamster is gone, and he won’t be coming back”, which sounded pretty permanent. So if that was what Doc Flanders meant by catching The Big One, Harold wanted nothing to do with it. He regretted missing whatever joys might have occurred during the five hours he was gone. Playing King On The Mountain with Chip and Ricky, crossing the tracks to the drugstore for a nickel Coke, and other such diversions that tantalize a boy on a summer afternoon.

So he vowed to be more careful. He started taking precautions, like gathering soft, forgiving things to land on, and looking both ways, and closing the cover before striking. Being careful served Harold well for a long time. It carried him relatively unscathed through teen angst, senior prom, driving, state college, the battle of Inchon, the ’57 tornado, 28 years of public school science teaching, 61 years of marriage to his “Lady Laura”, and countless hours encouraging their children and grandchildren to join them in adulthood.

The Big One stayed at a respectable distance throughout the years, venturing near only once during a tricky surgical procedure. Having survived that, Harold’s life was good, his health was strong, and he remained mentally fit.

But age eventually began to erode the bricks and mortar of his careful existence. One brick at a time at first: arthritis, bad knees, irritable bowel. Soon entire sections of walls: vision impairment, COPD, a broken hip slow to mend. And finally, a total structural collapse when Laura passed away. That was Harold’s final step in a beautiful journey that would have been cruelly shorter if not for his mom’s red tablecloth, which he still brought out
every Christmas. But now that he was ready for The Big One, it seemed in no hurry to oblige, as if to punish him for cheating it the first time.

With nowhere left to go and no one to go with him, Harold became an observer of life, enjoying the pleasures of others, but unable (or unwilling) to participate. His poor vision filtered out much of the remaining world left to him by Laura, and the effort to keep up with that world exhausted him. Like a weary traveler left waiting and forgotten at the terminal, he yearned to be taken home to rest.

Long ago, he had made a promise to be careful, and he had held true to it. But now, with no more King On The Mountain, nickle Cokes, and such, there was little reason to sidestep The Big One. Harold was fine with that, and he wished others who were not in his shoes could understand when he said things like “I’ve lived long enough” or “I’d like to just say goodbye and take a pill”. He wished they could comprehend that he was simply sharing his thoughts, not fishing for sympathy or threatening to end his precious life. A simple “I understand” would be enough, but, he admitted, for those who are still young, that might be a compromise too detrimental to their own journey.

So Harold waits patiently. He appreciates the value of life but does not fear losing it. He continues to be careful, because he believes how well one leaves life should be as honorable as how one lives life. He continues to take joy in small things and see the humor in all things, knowing that waking up breathing is the first blessing of the day. And his expectations are simple. When The Big One finally happens, and all are gathered in the chapel to say goodbye, he asks to be sporting his old red cape as a reminder of how this one Superman lived.
Correcting Misconceptions About AMD

Age-related macular degeneration (AMD) is a progressive disease of the retina wherein the light-sensing cells in the central area of vision (the macula) stop working and eventually die. The disease is thought to be caused by a combination of genetic and environmental factors, and it is most common in people who are age sixty and over. A reasonable estimate of the total number of people in the United States affected by all stages of macular degeneration is set at more than 8 million.

AMD can be a confusing condition. With so many facets to its diagnosis, symptoms, pathology, and treatment, it is difficult to understand everything about it in a ten-minute session with one’s doctor. This, in tandem with misleading advertising and dishonest fund-raising schemes, can create an atmosphere in which misunderstandings and disappointments flourish. In an attempt to help clear the air, this presentation highlights the most common misconceptions, each followed by a straightforward discussion based upon current knowledge.

Misconception #1: “AMD causes blindness.”

At its worst, AMD will damage only the center of the retina at the back of the eye. This area, the macula, which is comprised mostly of cone cells for precise color and detail vision, makes up less than 5% of the total retina, but it is responsible for about 35% of the visual field. When the cone cells begin to degenerate from age and inflammation, an affected person will eventually find it difficult or impossible to read, drive, or recognize faces. The peripheral vision, however, is left untouched, so macular degeneration does not, by itself, lead to blindness. Unfortunately, the peripheral field is made up mostly of rod cells, which are not designed for detail vision. Peripheral vision is, therefore, good only for general mobility and limited reading with magnification, but it still offers a view of the world.

In spite of central vision loss, many affected people are able to use their remaining vision to move about with little or no assistance and lead independent, productive lives. The most successful of them have learned to use a wide variety of assistive devices such as magnifiers, special bioptic glasses, navigation software, and electronic readers to maximize their peripheral vision and other senses. The answer to living well with low vision is to take advantage of technology while learning and developing assistive living skills through a good rehabilitation program. The only way a person will become blind from AMD is by being unwilling to give such alternative skills a chance.
Misconception #2: “AMD is a growing epidemic.”

Recent research has found that the risk of developing AMD has been dramatically lessening over three generations. For that matter, Baby Boomers (people who were born between 1946 and 1964) may experience better retinal health over a longer period of time than the two previous generations. The Baby Boomers and the new Generation X populations are already seeing comparable declines in AMD incidence, attributed possibly to better environmental conditions, sanitation, nutrition, and prevention strategies.

That said, the number of people with visual impairment or blindness in the United States is still expected to double by the year 2050. This is due to the aging population increase, though, not by any dramatic escalation of the disease risks.

Misconception #3: “Wet and dry AMD are separate diseases.”

Dry AMD is distinguished by white or yellowish deposits of cellular debris (“drusen”) in the retina. Drusen are toxic to the retina, but they are usually carried away by the blood vessels before harm is done. Unfortunately that cleansing process is diminished in aging retinal cells, which can lead to macular degeneration and central vision loss.

About 10-15% of dry AMD cases progress to the “wet” form, in which immature blood vessels grow and leak into the retinas of people who are genetically prone to having an aggressive inflammatory response. Inflammation is the body’s way of trying to deliver nutrition to injured or diseased tissue. The process is beneficial to the rest of the body, but it can cause retinal scarring and blocking of central vision if not treated in time.

Wet AMD is, therefore, secondary to age-related macular degeneration, not a separate disease state. The commonly-used term “wet” further describes the type of macular degeneration involving errant blood vessels. Use of the term “dry”, therefore, is unnecessary unless a distinction needs to be made between the two conditions.

Misconception #4: “Reading in dim light will make AMD worse.”

“Turn on the light”, said Grandma. “You’re going to ruin your eyes.” She meant well, but her suggestion should have been simply, “Turn on the light. You’ll be able to see better.”

Eyes are damaged no more by reading in dim light than are ears by listening to soft music. Actually, the wearing demand on the sight cells (photoreceptors) increases as the light grows brighter, which may prove
harmful to the vision of people with retinal deficiencies. The wisest approach would be to compromise between “enough light to see by” and “too much light.”

**Misconception #5: “Viewing cell phone, television, and computer screens damages the eyes.”**

No scientific evidence has yet revealed that light from such devices causes eye damage. The sun and full spectrum lamps which imitate the sun are the two strongest and potentially most harmful sources of blue light. By comparison, blue light intensity from cell phones, television, and computer screens is much less than either of those sources.

Frankly, light of any color has the potential of harming the retina. When the photoreceptors are exposed to light, they expend energy, which is later replenished by darkness (eg. sleep)—something called the visual cycle. But if exposure to light is intense and prolonged, the cells may not recover sufficiently. That kind of abuse will obviously take a toll on the photoreceptors over time, but the body’s natural defenses help protect most people from light damage throughout their lives. These defenses include dark irises, yellowing lenses, eyebrows, eyelids, and the compulsions of squinting and blinking. Blue-eyed people, whose irises do not filter blue light, are slightly more at risk, but wearing amber or orange lenses under direct sunlight can make up that deficit.

Again, light from electronic device screens—100 time less than the sun—is simply not strong enough to cause concern. Warnings about using such technology should be viewed with a certain amount of healthy skepticism until well-supported evidence is presented. Meanwhile, instead of avoiding digital screens altogether, it may be prudent to simply follow sensible practices like limiting screen time, taking periodic breaks, and taking advantage of light-filtering options.

**Misconception #6: “Cataract surgery causes AMD”**

Most retinal surgeons say that there is minimal danger of retinal complications from such surgery in the hands of experienced practitioners. Recent research has shown that patients who have cataract surgery do not have a higher risk of progressing to more advanced forms of macular degeneration, when compared to those who do not have cataract surgery.

Cataracts are very common in older adults, and can develop in approximately 50% of people between the ages of 65-75. About 70% of people over the age of 75 have cataracts. Cataracts can be removed only by surgery, which is successful in about 90-95% of all cases. The surgery
was previously known to cause retinal detachment in a small percentage of patients, but that risk is lessened now with extracapsular surgery, in which the posterior capsule of the natural lens is left in place to support the plastic replacement lens that is implanted during the operation.

Replacement of a clouded lens won’t restore vision lost from retinal disease, but it can significantly improve remaining vision and offer the examiner a clearer view of the retina. In light of the small risk, standard practice is to defer cataract surgery until vision loss from a cataract significantly reduces a patient’s quality of life. At that point, the benefit/risk ratio is sufficiently high to warrant the procedure.

**Misconception #7: “Stem cell replacement can cure AMD”**

The media has been full of news about stem cell therapy as a future treatment for AMD. It is true that, in trials, stem cells are replacing the retinal pigment epithelium (RPE) layer that supports the photoreceptors. And it is true that scientists are now beginning to replace damaged photoreceptor cells in animal models.

As exciting as the future of stem cell replacement is, however, it will not be a cure for AMD. Like a patch on a tire, it can restore vision for a time—maybe even until the end of life—but it does not address the underlying cause of the disease. The cure will more likely come from the field of gene replacement therapy, which is still several years down the road.

The day is fast-approaching when stem cell replacement will be available in the clinics. The possibility of actually restoring lost vision is exciting to think about, but it is important to remember that at this time, no stem cell treatments for any retinal diseases have been approved by the FDA for clinical use.

**Misconception #8: “Anti-VEGF drugs for wet AMD will reverse vision loss.”**

The anti-VEGF (antiangiogenic) drugs for treatment of wet AMD are designed only to block new blood vessel growth. The intent is not to restore vision, but to maintain current vision and prevent future damage. Some patients do see an improvement after initial injections, but that is mostly due to diminished swelling of the retina and/or gradual dissipation of collected blood.

While anti-VEGF drugs can effectively stop quick vision loss from uncontrolled blood vessels, most patients with wet AMD will continue to experience a gradual decline in vision over months and years until new
treatments for geographic atrophy (advanced dry AMD) are available. Such treatments are now in trials.

Patients who notice a decrease in vision while undergoing treatment for wet AMD should, therefore, not be too quick to blame the drug. If there is no further sign of blood vessel growth, then the drug is doing its job. But in the rare instance that blood vessel growth continues in spite of the treatment, the doctor may suspect that the patient has become resistant and will probably recommend switching to one of the other compounds. This has been shown to be safe and effective.

**Misconception #9: “Special glasses, eye exercises, electrical stimulation, acupuncture, and nutritional supplements can reverse AMD.”**

Nothing has yet been developed that will reverse AMD. That would have to come from a cure for aging itself—a discovery that would turn the world of medical science upside down. Special prismatic lenses can redirect the wearer’s focus onto a healthier part of the retina. Magnification can enlarge an image to where it can be seen better peripherally. Eye exercises, electrical stimulation, and acupuncture can improve blood flow, temporarily improving visual acuity. And certain nutritional supplements can help to slow the progression of the disease. But once the retinal cells have begun to show the effects of aging, no lens, device, supplement, or treatment can restore their youth or—for that matter—the youth of any other cells in the human body.

Until an anti-aging pill is developed, if ever, the best that can be done to fix the damage caused by years of wear on the body is to replace its parts. And that is being done successfully in many cases. They can replace lungs, hearts, kidneys, livers, and even bones, but replacing brain tissue, which is exactly what the retina is, presents a formidable challenge. So until that challenge is met, Band-aid treatments and workarounds will have to do.

**Misconception #10: “Doctors don’t understand how patients see.”**

When a doctor tells a patient that there is no change since the last visit, but the patient has been experiencing diminished vision during that time, it is not necessarily because the doctor does not understand. It is more likely that the patient has lost functional (everyday) vision that does not always show up in the imaging or on the acuity chart.

When the doctor says “no change” that usually refers to no apparent change in the anatomical structure of the eyeball, such as swelling or
separation of the retina, vessel growth, fluid collection, cataract formation, or problems with the vitreous fluid. “No change” might also mean that the number of letters visible to the patient on the acuity chart matches the previous test.

So why does the patient report worsening of vision? The answer could be that contrast sensitivity and/or brightness acuity has lessened. These functions are just as important as how many letters one can see clearly on a chart, but they are not identifiable in photos or computer images. Without testing specifically for them, the doctor has no way to know that a patient's everyday vision is being affected.

If a patient reports seeing worse when the doctor says there has been no change, that is when the patient might request a contrast sensitivity test and/or a brightness acuity test.

**Misconception #11: “Nothing can be done”**

By saying that nothing can be done about AMD, a doctor is saying that there is nothing medically that can be done other than anti-VEGF treatment for the wet form. AMD is incurable at this time, but hard-working researchers are close to providing answers. Meanwhile, there is much than can be done to maintain a person’s quality of life with visual impairment. Low vision rehabilitation can provide a strong foundation of knowledge and skills. Assistive devices and computer software programs equip low vision people with nearly every possible substitute for lost vision. Proper nutrition and health habits can slow the progression of the disease. And support organizations are ready to provide information and helpful social contact with others who share similar experiences.

A lot can be done for patients with eye diseases, but not solely in clinics. Living well with low vision requires looking outside of the limited box of medicine and recognizing all of the support, assistance, and opportunity that surrounds it. One good way to start is by visiting the resources at https://lowvision.preventblindness.org/resources/ or by calling 888-866-6148.
Detours
(A message to the MD Support Community)

Isn’t it amazing? You set out in life with a vision of a straight, smoothly-paved road along which you plan to travel unhindered into the future. But sometimes barriers block your way. You then have a choice to either stop and give up, or to shoulder your bag and take the detours.

And that’s the amazing part. There will always be detours, which will take you in some very interesting directions. And every time you return to the main road from one of those adventures, your bag will be a little heavier with the stuff you have picked up: souvenirs, hitchhikers, treasures, even some trash. It’s all in there, and good or bad, it is a unique collection.

You may be afraid right now; but, hopefully, your fear of the unknown will not stop you from taking the detours, because that’s where you will find all of us. And when we all finally get to the end of the road, we’ll throw down our stuff, give one another a big hug, and say, “Wow, that was some trip!”
Every Patient Can Be an Advocate

What do these six famous people have in common?
• Al Gore
• Malala Yousafzai
• Helen Keller
• John Walsh
• Martin Luther King Jr
• Michael J Fox

They are different in many ways, but they each possess at least one characteristic which sets them apart. They have a strong sense of empathy, making it impossible for them to remain silent in the face of adversity. They all believe in something so personally important to them that they can do nothing less than speak out for the sake of others. They are advocates.

Anyone can be an advocate. Formal training is not required, but the title is usually justified by knowledge, experience, and passion. The cause could be as far-reaching as human rights, education, and poverty, or it could be as simple as speaking out about litter in the neighborhood. Advocacy is usually ignited by a significant personal experience, and then fueled by natural born empathy.

One of the most important causes is patient advocacy. That is, taking an active part in improving treatment and health care for people who cannot, or do not, always speak for themselves. Such advocacy can be directed by any caring individual toward one or all of four groups of people:
• Medical providers
• Community members
• Family members and friends
• Elected officials

Here are some suggestions about how a patient can best advocate within each group:

MEDICAL PROVIDERS
• Help professionals to be professional.
  Provide them with trusted information and resources for distribution to patients.
• Volunteer for clinical trials.
  Find trial information at clinical trials.gov and centerwatch.com.
• Be an informed patient.
Sign up for newsletters from low vision organizations and media news alerts.
See links to trusted information about Eye Diseases and Conditions.

COMMUNITY MEMBERS
- Seek out speaking opportunities
  Everyone has a story to tell, and it doesn't have to be a Pulitzer prize winner.
- Participate in or initiate a fund-raise
  Whether it is for research or educational outreach, every dollar is important.
- Be an Internet scout for those who are unconnected
  Many people still have no access to the Internet. Be a go-to source of information.
- Be an informed consumer
  Get the best deals by reading customer reviews and business reports before making major purchases.
- Speak up about misleading advertising, and report consumer scams
- Speak out in favor of good efforts
  One spoken compliment or thank you note can go far with vision care professionals and service providers.
- Donate generously but cautiously
  Consult with Guidestar, Charity Watch, Charity Navigator, and other good watchdog agencies.
- Be a model patient
  Show others how to live well with low vision by displaying positive actions, courage, and knowledge.

FAMILY MEMBERS AND FRIENDS
- Educate with empathy
  Ignorance can best be eliminated with understanding and gentle teaching.
- Teach by example.
  Don't just talk about correct behavior, model it.
- Be honest
  Communicate openly, but discriminately. Don't dwell on the subject, but don't hide it either.

ELECTED OFFICIALS
• Keep up on legislation affecting the low vision community, then:
  --Decide what is right, and stand up for it.
  --Encourage other patients to express the low vision community’s needs and concerns to their legislators.
  --Provide government officials with reasonable solutions, then offer to help carry them out.

Society needs advocates. Not everyone is able to take necessary action, due to lack of personal resources, physical or mental capabilities, finances, or human support. So others need to step in. And by doing so, such caring individuals not only offer a necessary gift, but they themselves reap the pleasures of accomplishment and purpose. Not everyone can be a Helen Keller or a Martin Luther King, but striving for their heights is a worthwhile effort.
Former Driver, Retired With Honor

Dear Driver’s License Inspector,

Yesterday you granted me the privilege of driving for another six years. Because I could read the largest line of numbers with my one remaining eye under perfect lighting conditions, you determined that my vision was good enough to allow me behind the wheel.

But do you know I have a chronic retinal disease which could take away my remaining functional vision before you test me again? Do you know I have poor night vision, serious problems with glare, and low contrast sensitivity? Do you know that I have backed full speed into a tree I didn’t see, almost pulled into the path of a truck that appeared out of “nowhere”, and drove the wrong way down a one-way street? You didn’t ask me. Instead, you have allowed me to negotiate the highways with drunks, druggies, neurotics, and sleep-deprived drivers all speeding less than ten feet apart on the way to places they just have to be, no matter what the cost. Do you really want to add me to the mix?

In case you are having second thoughts, I want you to know that I have decided to be one less driver for you and your family to worry about. Like a certificate for over a half century of distinguished service, my shiny new license, and its mug shot of an old guy I just met, will remain safely tucked away behind my Medicare and AARP membership cards. It was a tough decision, but someone had to make it.

Thank you for your trust in me, but now the only way I am going to meet your family on the road is as that guy smiling at you proudly from the passenger window.

Sincerely yours,

A Former Driver
Retired with Honor
Hidden Disabilities: A Social Dilemma

Margaret’s Story

"I was making my way down the sidewalk. I heard the clack-clack of skateboard wheels coming at me head-on. I couldn’t see which way to step, so I just froze in place, hoping the child would have good maneuvering skills.

"He didn’t. He collided with my bad hip, and his ride escaped into the street. He ran after it, and I was startled at the sound of a blaring horn and tires scraping on loose gravel.

"He returned unharmed, thank goodness, and slammed his skateboard back onto the walk. He stood in silence for a few seconds, probably scowling at me and waiting for an apology. Then, before I could explain my visual impairment, he was off again, leaving me standing there, pondering how I should get my mail from then on."

Why did this happen?

The simple answer is "lack of understanding". Dr. Thomas Behler, a sociology professor, sees increased awareness and more frequent interaction as paths to better social understanding of disabled individuals. Professor Behler credits government intervention and organizational advocacy with improvements made over the past several decades. He is concerned, however, that the evolution has been slow, and mistakes are still too frequent. (1)

Few will argue that awareness and interaction are important to understanding, but what is the catalyst? According to the Centers for Disease Control, “Disabilities can affect people in different ways, even when one person has the same type of disability as another person. Some disabilities may be hidden or not easy to see.” (2)

How could the boy have known?

It is easy to identify obvious physical limitations in a person, and then to interact with that person compassionately. One cannot, however, as readily identify conditions that do not obviously restrict a person’s mobility or physical capabilities. The CDC says that hidden conditions can seriously affect a person’s vision, mental abilities, communication skills, hearing, and social relationships. So how can a person avoid misunderstandings and social gaffes when dealing with individuals who display no immediate signs of disabilities? Is the woman in the checkout line visually impaired, or has
she never learned how to count change? Is that student hard of hearing, or is he simply not paying attention?

**Where does capability end and disability begin?**

An inherent problem is that the definition of “disability” is vague. At what point does one move from capability to disability? Merriam-Webster says disability is “a condition (as one present at birth or caused by injury) that damages or limits a person's abilities.” (3) The Department of Health and Human Services holds that “disability doesn't mean unable, and it isn't a sickness. Most people with disabilities can - and do - work, play, learn, and enjoy full, healthy lives.” (4)

The Americans With Disabilities Act defines “disability” as a legal term, rather than a medical one, including people who have a record of such an impairment, even if they do not currently have a disability. (5)

The Social Security Administration publishes a "bluebook" of disabilities qualified for benefits, and the list is updated or modified as new cases are addressed. (5)

In another attempt to clarify, The World Health Organization has published the International Classification of Functioning, Disability and Health. This provides “a standard language for classifying changes in body function and structure, activity, participation levels, and environmental factors that influence health [in order to] assess the health, functioning, activities, and factors in the environment that either help or create barriers for people to fully participate in society.” (6)

A number of writers have tried to refine the meaning of “disability” by differentiating it from similar terms, such as “inability”. Without getting bogged down in semantics, however, suffice it to say that the search is not yet over for the most appropriate term and definition to satisfy all circumstances. And this confusion can make appropriate social interaction challenging.

**Something is missing**

If awareness and interaction are necessary for understanding a disabled person, and the disability is not visible or well-defined, and no intermediation exists, then this stool has only two legs. Maybe the missing third element is something like empathy, the ability to understand and share another person’s feelings. One may be aware of another’s disability and even spend a good deal of time around that person, but without empathy, compassionate interrelation will not occur.
In her book, *On the Problem of Empathy*, early 20th-century German phenomenologist Edith Stein wrote that the capacity for empathy can be innate (“primordial”), and it can also be “given” via relationships with others. It can be activated by memories of one’s own personal experiences, but it cannot be forced to occur [i.e. taught]. Having walked in someone else’s shoes is the best way to learn it, but to be empathetic, one must possess good listening habits, confidence in one’s own position, and honest self-concepts. (7)

Psychologist Daniel Goleman, Ph.D. distinguishes three types of empathy:

1. Cognitive empathy, the ability to see the world through others’ eyes.
2. Emotional empathy, the ability to tune in to another person’s feelings.
3. Empathic concern, an expression of caring about another person. (8)

A truly empathetic person (empathist) innately possesses cognitive and/or emotional empathy in all situations. Empathy in most people, however, is selective, limited to situations that have already passed the owner’s personal tests of awareness and interaction. A woman might, for example, feel compassion for a crying infant on an airplane, while she might roll her eyes at a grown adult suffering an anxiety attack. Selective empathy is not helpful to disabled people who must interact with society in general. Outside of their personal support systems, they are vulnerable to ignorance and lack of empathy. They are fortunate when a true empathist comes along.

**Whose fault was it?**

The boy was evidently unaware that Margaret could not see him, and he expected her to clear the way. Margaret might have taken her long cane with her, which would have signaled her poor vision, but she probably knew the short route well enough that she didn't think she needed it.

Neither the boy nor Margaret were totally at fault. The boy may be more careful next time, but what about other people who have not had his opportunity to learn? Even if she takes her cane along, how can she expect to feel safe during future walks to the mailbox?

Unfortunately, Margaret cannot count on society to change overnight, if ever. It may be on her to become proactive. Perhaps she could make an effort to socialize more with her neighbors in order to provide them and their children information about her vision impairment. She might even ask the boy to accompany her to the mailbox as a special skateboard police escort. This kind of proactivity would incorporate awareness and interaction, which might lead to better understanding all the way around.
And, as an extra benefit, the people who could then become empathetic to her situation might be able to generalize that empathy and apply it to other circumstances.

**The Bottom Line**

Awareness and interaction can lead to understanding, and empathy transports a person from understanding to compassion. If individuals with disabilities are to be treated fairly — for that matter, if anyone is to be treated fairly — society unequivocally needs to embrace this principle. Until then, disability will continue to be a handicap.

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Hidden Thoughts of the Visually Impaired
Presentation to the International Low Vision Support Group
January 2018

Those of us who are affected by vision loss often feel like we are in a vacuum, dealing alone with the physiological and emotional effects on our personal lives. We hesitate to discuss our concerns with anyone, so we often remain stoic. We have few outlets for what we consider to be our unique problems, and if we do find an outlet through a support system of similarly affected individuals, we tend to keep silent. Everyone else, we think, is so positive and accepting of their conditions, it would be a shame to bring them down.

Over the past couple of decades as a low vision educator, I have conversed one-on-one with countless visually impaired seniors. I have been privy to their hidden thoughts, and I have learned that we have much more in common than we think. It’s just that we don’t often have the time, opportunity, or audacity to reveal our sameness to one another. This is unfortunate, because we need to know we’re not alone with our thoughts. So I have decided to reveal the most common hidden thoughts that have been shared with me. Names withheld, of course.

Here, in no particular order, are 30 comments I hear most often. Some of them can be unsettling, and even more so, because I offer no remedies here. Instead, I hope, by discussing these issues in group environments, people might derive a better understanding of their own hidden thoughts. Opening the curtain like this and seeing ourselves mirrored in others may help us realize that we have lots of compassionate company.

1. I see things and people that aren’t there. It’s a harmless condition called Charles Bonnet syndrome that affects lots of people with low vision. I don’t tell anyone I see things, though, because they might think I’m crazy.

2. I see things that ARE there, but I don’t mention it. It’s just too tedious to constantly explain how relatively good the healthy parts of my vision are. I feel dishonest sometimes not telling people I actually see pretty well under certain conditions; but I just get tired of teaching something that cannot be totally understood by someone who hasn’t walked in my shoes.

3. I’m embarrassed when I don’t recognize close acquaintances. They always forget that I can’t make out their faces, and I feel awkward reminding them to identify themselves. That makes me look like I’m just fishing for attention. Do they really forget to identify themselves, or do they just not care enough to make the effort?
4. I can’t find what is right on top of my messy desk. Clutter makes it difficult for me to distinguish individual objects, because there is too much visual input for my eyes to handle. I feel stupid when I can’t see something that’s right in front of me.

5. It’s humiliating that I read like a third grader. I used to be a fast reader, but because of my vision loss, I need more time to discern words and sentences. I know I can increase my reading speed with practice and professional help, but I need to decide if I want to put forth the effort.

6. Maybe I’m too old to keep trying to find new ways to see. Maybe I should just accept my impairment and spend my remaining time enjoying what I have. What would be so wrong in letting other people do things for me now?

7. I walk slower than I used to, and that makes me look old. I could use a support cane or a walker, but what would my perfectly able friends think? How embarrassing it would be for them to pity me!

8. I’m reluctant to use a blind cane or a guide dog. Both take a large commitment to practice and training, and I’m not sure I want to be responsible for another pet at this time in my life. Also, wouldn’t a cane or a guide dog advertise my visual impairment and make me an easy target for predators?

9. I have trouble understanding speech. Since my vision makes lip reading difficult, people need to enunciate better. And speaking louder doesn’t help! And why do TV shows and movies think they have to play music all the time? Don’t they know how that interferes with understanding speech?

10. I misinterpret what people say. A roll of the eyes or a hint of a smile are all a sighted person needs to distinguish between sarcasm and honesty. Without those kinds of sight cues, though, I sometimes have to ask the person’s intent, which makes me appear dense.

11. I sometimes get tired of overly-positive people. “Look at the good side,” my friend likes to say. She may be playing Pollyanna for my benefit, but she needs to realize that I can handle serious discussions. It’s hard to see a lot of positives in losing independence and capabilities, so I would appreciate a little more honesty and less chirpiness.

12. I have “down days” for seemingly no reason. I know that without valleys there would be no mountains, but living with low vision, those days in the valley can get awfully long.

13. My vision isn’t as good as my doctor says. My eyes are tested under the best conditions in the clinic, but my normal environment will not always
be so still, well-lit, or clear as those vision charts. The doctor is good at diagnosing, but I’m actually a better judge of how I see in real life.

14. I enjoy sitting in dim light. Which seems to bother my family, but it’s easy on my eyes and healthy for my retina. I still enjoy opening the curtains on a beautiful day.

15. I hate losing my independence. I wish people would realize that I’m still the captain of my own ship. As long as I’m of sound and open mind, I think I will be the best judge of what is good for me.

16. I get easily frustrated or angry. Who wouldn’t? This disease has attacked me silently from the inside, and there is not much I can do to avoid the damage it can cause. It’s never going to go away, either, so I feel like I’m living with the sword of Damocles hanging over my head. That would tend to make a person a little hard to live with at times!

17. I feel as if my family and friends don’t care. If I say anything about my vision problems, they often just nod their heads sympathetically or change the subject. Even worse, they offer suggestions like getting new glasses or trying the new pill they heard about on TV. I think I’ll just keep news about my condition on a need-to-know basis.

18. I feel as if my doctor is dismissing me. He talks to me, but not with me. I’m afraid to ask questions, because he is always in such a hurry, with more patients waiting in other rooms. I wish he would at least tell where to go for answers and support.

19. I sometimes suspect that I’m getting unnecessary tests and treatments. I hate to think it, but is my doctor just trying to pad her pocket to pay for all of those staff members and expensive instruments?

20. Sometimes I think God gave me more than I can handle. I know they say he wouldn’t do that, but maybe he gives me more than I can handle so I will see how much I cannot handle. That would make sense, because it would give me the humility to accept help graciously. No matter how well I learn to be independent, there will always be times when I simply cannot handle a problem on my own.

21. I don’t want to use a computer or smart phone. High technology overwhelms my brain and tests my patience. I know I’m not too old to learn, but maybe I’m too old to want to learn. That’s okay, isn’t it?

22. Is science ignoring me? In my lifetime, scientists have halted epidemics and cured all kinds of infectious diseases, so when is it my turn? My eye disease isn’t life threatening, but it is quality-of-life threatening, which can be just as distressing.

23. If a cure is found, I’m afraid I won’t qualify for it. There is a chance that my age, treatment history, stage of development, or access to care
may preclude me from certain cures. I know it would be good news for others, but would I be a rotten person if I felt cheated?

24. I feel guilty about the health and nutrition choices I make. I should eat better and exercise more, but sometimes I have an affair with a doughnut or use the rain as an excuse to not take a walk. Anyway, my doctor says my psychological health is important, too. So I may die a few minutes earlier because of a doughnut, but I'll die happy.

25. I sometimes think my life isn't worth living. I once had a social life, good health, and a hopeful future. Now my poor vision, combined with problems of aging, is putting the brakes on everything that used to get me out of bed in the morning. My days are all the same, and my nights are growing longer. I can't do many of the things that used to keep me busy. And when I'm not busy, time moves so awfully slow. What's the use in living if I can't live well?

26. I get tired of hearing how much worse off I could be. True, some people are blinder, poorer, and more disabled than I, but there are also those with good eyes, more money, and perfect health. Why should I feel better than the unfortunate any more than I should feel worse than the fortunate? All the empathy in the world for others won't keep me from sometimes throwing a pity party and inviting only myself.

27. What did I do to deserve this? Maybe I should have eaten better, or quit smoking, or gotten more exercise, or stayed out of the sun. Or maybe it was bad DNA, or not enough days in church. Or maybe I should think more about the bridge than the water that has passed underneath.

28. I'm losing my self confidence. I realize that, as I lose more vision, I'm becoming more vulnerable to mistakes. This causes me to be less courageous about tackling new projects, making me look lazy or unmotivated. I have seldom lacked in ambition, so I worry that others might be thinking that of me.

29. I'm increasingly obsessive. My family and friends think I'm persnickety, but my future self will appreciate how considerate my current self is in keeping things and thoughts organized.

30. Sometimes I get tired of being independent. I know, with a little effort and patience, I can do almost everything by myself. But there are times when it would be nice if I could say, "Please help me" without looking incapable.

_____________________________________________________________________

That's it. 30 hidden thoughts of the many visually impaired seniors I've met. I trust that, through their honesty, they are offering their company to
help us realize we’re not alone. By shining a light on things we might think are too dark to share, I hope we will be able to see them more clearly. And clarity can often provide relief.

This presentation is meant to be discussed, either with a group of like-minded people or as a way to help us communicate with a friend or loved one. These musings are normal, even common, among people who are living with vision loss. Keeping them inside is not only unhealthy for the people who own them, it is selfish and unfair to those who need to hear them.

Thank you for understanding how important we are to one another.
How Cope-able Are You?

Cope-ability is something everyone needs at some time or another in the course of life, particularly when experiencing loss of eyesight. It is something deep inside that waits until it is needed. When summoned, it rises to the surface, ready to offer comfort in the knowledge that everything will be all right.

But what is it? Is it part of the original human hardware, or does it need to be built? If it needs to be built, then what materials are required?

Some people seem to be born with cope-ability. Compare different babies. Some of them just deal with the stresses of life as a newborn. No one shows them how, they just do it. Most babies, however, melt down several times a day for no discernible reason. They are fragile, insecure little eggs, and their emotional insides are easily scrambled.

Some emotionally labile people survive through adulthood by depending upon family and friends for support. That may be good in the short term, but most people manage to eventually slap together their own specially designed cope-abilities using materials gathered from living the greater part of a life.

Your Cope-ability Strengths

Below is a list of thirty such materials which have proven to be highly durable by those who are walking the AMD road. Discover your cope-ability level by counting those habits which you practice on a regular basis.

1. You deal with problems one at a time, rather than letting them pile up.
2. You compose lists of positives and negatives when a tough decision has to be made.
3. You identify escape routes in case plans go awry.
4. You practice techniques such as counting to ten or controlled breathing during times of stress.
5. You let go of thoughts that really don’t matter.
6. You use yesterday’s lessons to plan for tomorrow.
7. You enjoy the present, because you realize that it is always the present.
8. You expect the best, but prepare for the worst.
9. You give yourself the gift of time.
10. You never say what you think until you’ve thought.
11. You don’t sweat the small stuff, but you work hard on the big stuff.
12. You maintain a bit of knowledgeable cynicism.
13. You believe that miracles can happen.
14. You let your enthusiasm show.
15. You look for hope in everything.
16. You love and laugh a lot.
17. You make no excuses.
18. You lay no blame.
19. You accept responsibility for your own actions.
20. You look for possibilities inside yourself.
21. You are your own best friend, cheerleader, and entertainment director.
22. You get plenty of rejuvenating sleep.
23. You eat and drink well.
25. You reward yourself for little successes.
26. You forgive yourself for little failures.
27. If you feel like your glass is half empty, you get a smaller glass.
28. You think of strangers as your friends.
29. You embrace change while respecting tradition.
30. You laugh and cry enthusiastically, because you know how healthy that can be.

Total: ___/30

_________________________________________________________

Your cope-ability score:

30/30: You should think about starting a talk show. The world needs to learn from you.

22-29: You will be successful at this low vision thing. Congratulations!!

15-21: You will do fine if you can raise your score as soon as possible. Make that your most immediate goal.

8-14: You have some work to do. Start with the easiest to change, then build on those successes.

0-7: You are as delicate as an egg shell. Hopefully, this book will give you the strength you need to cope with the challenges of AMD. If you cannot get your score up to at least 20, please consider talking to someone who can help you sort out your thoughts and the direction you want to take.
I Can’t See What You Mean

Our inability to see facial expressions can cause difficulty understanding implicit meaning. How, then, are people with blindness or low vision supposed to interpret speech successfully in the absence of visual cues? The answer is actually fairly simple. We listen.

People can communicate their meaning solely by the words they choose and by the context of those words. How they utter them, however, is just as important. Consider how the meaning of this sentence changes depending upon which words receive emphasis (indicated by upper case font).

"Set your glass on the COASTER." (meaning not on the TABLE)
"Set your glass ON the coaster." (meaning not NEXT to it)
"Set your GLASS on the coaster." (meaning not your PLATE)
"Set YOUR glass on the coaster." (meaning not MY glass)
"SET your glass on the coaster." (meaning don't SLAM it on the coaster)

Theatrical directors expect their actors to enhance the meaning of their speech by employing both physical and vocal devices, with the latter usually carrying the most weight. Physical, especially facial, expression can be lost to the balcony audience, and it is totally inapplicable to reader's theater, radio, audio books, and other nonvisual performance media. Proper inflection, on the other hand, leaves little room for misinterpretation.

Fortunately, we humans have learned, or have evolved, to use inflection for meaning. Inflections may differ among cultures, but they are tightly and uniquely tied into every language. So when I listen to someone, my wife for example, I rarely need to see her face. Which words does she emphasize? Where does her pitch rise or her volume fall? Why did she pause just then? Chris and I have little problem understanding one another's meaning. Not necessarily because we've been married for many years, but because we share the linguistic style of a common language. When she speaks, I don't have a problem understanding what she means. If she gently says, "Place your glass on the COASTER", I know she is just trying to help me find where to set my glass. But if her tone is stronger and reprimanding, I not only know where to place the glass, I know Chris is tired of wiping water rings off of her vintage oak coffee table.

Okay, so if I listen to tone and inflections, I'll be able to catch meanings most of the time. And if I can't make the call, I can always politely ask for clarification. But what about when it's my turn to talk? It may be easy to catch Chris's meaning when she speaks to me, but how do I read her
reactions when she's listening? Is she nodding (understanding)? Is she closing her eyes and shaking her head (disagreeing)? Or maybe she's not even looking at me, just wondering when she can return to her magazine.

Since we frequently display our thoughts nonverbally during conversation, visualization is an important part of mutual understanding. We smile, roll our eyes, smirk, and drop our jaws in dismay. It is important that we are aware of these kinds of reactions so we know how to sculpt our talk. But how? Again, by listening.

If I listen carefully, I might hear Chris making subtle sounds. Common sounds such as "hmm", "uh-huh", and "humph" cue me into her thoughts. If, however, she makes no sounds, I could invite her response with questions like, "Do you agree?" or "Right?" I might even break her silence by saying, "Are you still there?" Normally, that would sound sarcastic, but it is perfectly reasonable coming from someone who can't see. It might even be an effective way of reminding the listener that we are using our ears, not our eyes.

When at least one dialogue partner is visually impaired, it should sound like conversing over the phone. We have all done that, and we have learned that a little extra effort is required in such situations when vision isn't possible. All we have to do is apply telephone conversation techniques to in-person communication.

Nothing can replace the benefits of vision in conversation. The ability to see the thousands of combinations of macro- and micro-expressions passing over the face is extremely beneficial to successful interaction. We can, however, do very well if we let our ears attend not to just the words, but to the timbres and sounds that accompany them.
I Can’t See What You’re Saying

Why do we visually impaired people also seem to have trouble understanding speech? Do we really need people to speak louder to us, as they are often prone to do? The answer may come from recent findings at the University of Utah. A study reported in the journal PLOS ONE has shown that a phenomenon called the McGurk effect may be the cause.

Scottish cognitive psychologist Harry McGurk first identified a link between hearing and vision in the 1970s. And now, University of Utah bioengineers have pinned the cause on the way our brains process sound. By recording and analyzing activity in the temporal cortex, the researchers found that much of what we understand is perceived more through our eyes than through our ears.

This discovery may be of value to treatment of conditions such as dyslexia, and it may help scientists better understand how speech is developed in infants. But of more immediate importance to us is that it helps explain why we seem to have increased difficulty understanding speech as our vision declines.

When normally sighted people converse in person, much of what they understand is visual. In other words, they are reading lips. Take away the visual input, however, and they may as well be talking on the telephone. And we have all experienced difficulty trying to relay information on the phone. Without vision, for example, the word "bat" could very well be heard as "vat" or "that". That's why NATO and Western Union developed phonetic alphabets for spelling words aurally (Alpha, Beta, Charlie, etc.).

The bottom line is, low vision people are not necessarily hard of hearing. It might be more correct to say we are phonetically challenged. That places the responsibility on the speaker, who should enunciate clearly while speaking at an appropriate volume and slightly slower speed.

"I can't see what you're saying" now takes on another meaning, and we hope it will be understood by those with whom we converse.
Is Blindness The Worst Ailment?

A recent online nationwide poll (1) has joined similar past studies in revealing that people consider vision loss to be the “worst ailment that could happen to them relative to losing memory, speech, hearing, or a limb.”

The researchers’ intent was to “underscore the importance of focusing on preservation of eye health and the public support for vision research.” Most of the respondents supported prevention and treatment of eye and vision disorders as a priority, which may help to guide policy and funding strategies. The poll, however, also unintentionally surfaced the need for a stronger emphasis on education about the meaning of vision loss.

It seems that most people equate uncorrectable vision loss with blindness. A major part of public education should include awareness of the fact that individuals affected by most eye diseases do not go blind. Defects in their ophthalmic systems can prohibit seeing well, but total blindness is very rare. (2) The majority of the visually impaired population is at least partially sighted and capable of handling most daily living activities with the use of assistive optical and non-optical devices. Those who are without functional vision can benefit also from non-optical devices, in addition to adaptive techniques, Braille, and mobility aids.

99% of all normal daily living activities can be accomplished without eyesight. (3) Blindness at any level is manageable with proper education and rehabilitation intervention. Continued support of vision research is indeed necessary, but to believe that blindness is “the worst ailment that can happen” is to exaggerate the comparative functional value of eyesight and to deprecate the burdens of truly debilitating conditions. More significantly, such thinking reinforces the fear of losing vision, which can lead to chronic depression and devalued quality of life in those who are faced with it.

A large number of resources are available for those who would like to learn more about living well with vision loss. Living with blindness is challenging, but it is not as dreadful as the unenlightened might believe.

Sources:
(2) Vision Problems in the U.S. Published online by Prevent Blindness.
(3) An Examination of Sensory Contributions to Independent Activities of Daily Living. Dan Roberts. (Published online 2011)
Is Brittany Blind?
A presentation to students of Music Therapy at the 
University of Missouri, Kansas City
December 7, 2004

Introduction
Ten-year-old Brittany has been a music and composition student of mine for three years. She was born with a rare condition called anophthalmia, which translates as "without organs of sight." Most of society, therefore, classifies her as a blind person.

Webster's Dictionary defines "blind" as "without sight" and without "the faculty of vision." It also defines "vision" as "the faculty of seeing [and] sight." The terms are used interchangeably, meaning that Brittany, as a blind person, is without sight or vision.

Since about 80% of a human's total sensory experience is gathered by at least one eyeball for transmission to the brain, it would seem that Brittany is operating at a significant deficit. Nature, however, has assigned those ophthalmic functions to her senses of hearing, touch, taste, and smell, in addition to specially-developed mental abilities that most people will never acquire. She possesses heightened levels of conceptualization, retention, audio frequency recognition (i.e. "absolute pitch"), spatial awareness, and creativity. When owned by people with all five senses operating at capacity, those abilities are called "gifts." To Brittany, however, they are necessities, because they give her sight. Her abilities appear preternatural; but to her, they are like sonar to a bat: vital alternatives. Because of whatever rewiring her infant brain underwent, she can see as well as (or better than) most of us, just in different ways. Should we then label her "blind?"

Five Questions
I began my pursuit of the answer to the question "Is Brittany blind?" by listing all of the definitions for each of the words "see," "sight," "vision," "eye," and "blind" from Webster's Online 1913 Dictionary and Princeton University's WordNet Dictionary. For clarity, I eliminated duplicate definitions and then formulated them as yes/no questions about Brittany. All of my decisions were based upon objective personal opinions which I formed as her private teacher. The exercise, though blatantly unscientific, proved to be enlightening. [Note: For the benefit of people using text readers, my "yes" or "no" response follows each definition.]
Question 1: Can Brittany see?

(Source: WordNet Dictionary)
Can she . . .
1. make sense of? assign a meaning to? [yes]
2. perceive mentally? [yes]
3. get to know or become aware of, usually accidentally? [yes]
4. be careful or certain to do something? make certain of something? [yes]
5. consider or deem to be? regard? [yes]
6. deliberate or decide? [yes]
7. find out, learn, or determine with certainty, usually by making an inquiry or other effort? [yes]
8. match or meet in card games? [yes]
9. receive as a specified guest? [yes]
10. imagine; conceive of; see in one's mind? [yes]
11. come together? [yes]
12. accompany or escort? [yes]
13. go or live through? [yes]
14. perceive or be contemporaneous with? [yes]
15. perceive by sight or have the power to perceive by sight [cf Question 2]? [yes]
16. see and understand? [yes]
17. observe, check out, and look over carefully or inspect? [yes]
18. watch? [yes]
19. observe? [yes]
20. date regularly? have a steady relationship with? [yes]
21. go to see for professional or business reasons? [yes]
22. go to see for a social visit? [yes]
23. visit a place? [yes]
24. take charge of or deal with? [yes]

(Source: Webster's 1913 Dictionary)
Can she . . .
25. perceive by the eye [cf Question 4]? behold? descry? view? [yes]
27. follow with the eyes or as with the eyes [cf Question 4]? regard attentively? look after? [yes]
28. have an interview with; especially, to make a call upon? visit? [yes]
29. fall in with? have [social] intercourse or communication with; hence, have knowledge or experience of? [yes]
30. accompany in person? escort? wait upon? [yes]
31. (Physiological) have knowledge of the existence and apparent qualities of by the organs of sight? [no]

Question 2: Does Brittany have sight?

(Source: WordNet Dictionary)
Is she capable of . . .
1. the act of looking or seeing or observing? [yes]
2. the ability to see [cf Question 1]? the faculty of vision [cf Question 3]? [yes]
3. a range of mental vision? [yes]

(Source: Webster's 1913 Dictionary)
4. view[ing]? [yes]
5. opinion? judgment? [yes]
6. [Physiological] perception of objects by the eye[ball]? [no]

Question 3: Does Brittany have vision?

(Source: WordNet Dictionary)
Does she possess . . .
1. the ability to see [cf Question 1]? [yes]
2. the perceptual experience of seeing [cf Question 1]? [yes]
3. imagination? [yes]
4. sight [cf Question 2]? [yes]
5. visual modality? [yes]
6. visual sensation? [yes]
7. visual sense? [yes]

(Source: Webster's 1913 Dictionary)
Is she capable of . . .
8. the act of seeing external objects [cf Question 1]? actual sight [cf Question 2]? [yes]

Does she possess . . .
9. the faculty of seeing [cf Question 1]? sight [cf Question 2]? [yes]
10. [Physiological] one of the five senses, by which colors and the physical qualities of external objects are appreciated as a result of the
stimulating action of light on the sensitive retina, an expansion of the optic nerve. [no]

Question 4: Does Brittany have “an eye”?

(Source: Roget’s Thesaurus)
Is she capable of . . .
1. accountability, vigilance, consideration, contemplation, conviction, discernment, estimate, examine, farsightedness, feeling, frame of reference, general belief grasp, judgment, keep[ing] in view, mental outlook, observation, personal judgment, view, viewpoint, theory, thinking, thought? [yes]
   Does she possess . . .
2. [a] mind? [yes]
3. the faculty of seeing [cf Question 1]? power or range of vision [cf Question 3]? hence, judgment or taste in the use of the eye, and in judging of objects? [yes]
4. The action of the organ of sight; sight, look; view; ocular knowledge; judgment; opinion. [yes]
5. [Physiological] the organ of sight or vision . . . properly the movable ball or globe in the orbit, but [also] the adjacent parts? [no]

Question 5: Is Brittany blind?

In order to answer this target question completely, I needed to respond to a few more definitions, this time describing Brittany in reference to the word “blind."

(Source: WordNet Dictionary)
Is she . . .
1. [a person with] severe visual impairments? [no]
2. unable or unwilling to perceive or understand? [no]
3. unable to see [cf Question 1]? [no]
4. dim, dim-sighted, eyeless, irrational, sightless, unperceiving, unperceptive, unreasoning, unseeing, unsighted, visually challenged, visually impaired? [no]

(Source: Webster's 1913 Dictionary)
5. destitute of the sense of seeing, either by natural defect or by deprivation; without sight [cf Question 2]? [no]
6. not having the faculty of discernment; destitute of intellectual light; unable or unwilling to understand or judge [no].

7. undiscerning; undiscriminating; inconsiderate. [no]

8. befogged, benighted, bit, choked off, cloaked, closed, clouded, compulsive, deprived of sight [cf Question 2], dim-witted, eyeless [cf Question 4], imperceptive, impervious, impetuous, impulsive, in a cloud, in a fog, inconsiderate, indeterminate, indiscriminate, indistinct, insensible, insensitive, irrational, mindless, misty, muddled, muted, mysterious, oblivious, short-sighted, stupid, uncomprehending, unconscious, undiscerning, unenlightened, unpersuadable, unreasoning, unthinking, unwilling, unwitting, visionless [cf Question 3]? [no]


I concluded that, other than physiologically, Brittany can see, she has sight, she has vision, and (by the majority of definitions) she even has "an eye". In place of ophthalmic vision, she sees by sensory substitution. My job as her teacher, therefore, is to search for educational approaches suited to her unique learning processes. Basically, that means tossing out everything that requires ophthalmic input or photographic visualization (i.e. reading of musical notation) and using an extended version of a familiar method already set in place by Shinichi Suzuki in the mid-twentieth century.

Suzuki realized that making music does not have to depend upon reading notation. Such dependency began to evolve about 800 years ago when the compendium and intricacy of musical compositions surpassed the limits of the average person's memory and skills. Brittany, however, is fully capable of creating, replicating, and remembering intricate music without notation, so imitation is her modus operandi. Through this gradually-advancing approach, she is building technique, studying the elements of melody, harmony, rhythm, and form, and learning the literature. Evidence of this training shows up in her compositions, which display ever-increasing levels of sophistication.

In spite of the blessings of sensory substitution, Brittany still has challenges. She lives in a world designed by ophthalmic people who create stairs, sharp corners, stop lights, printed words, color-coding, and poles in the middle of nowhere; who set their clocks by the daylight, judge one another by physical appearance, and communicate through pantomime; who turn red with embarrassment, blue with the cold, green with envy, and white with fear; who lower their eyes in shame, stare in defiance, and gaze in awe. Worst of all, Brittany lives in a world where "I see" means "I understand."
"Somebody Moved the Door"

Prior to her piano lessons at my school, Brittany practices in another room down the hall, just past the waiting room. When it is time for our session, she exits the practice room, turns right, walks a few steps, and turns left into my studio. In the early days, I guided her, but she does very well without me now, except one time.

As she was getting ready to make her usual right turn, another student opened and shut the door to the waiting room just ahead of her. She immediately corrected by heading toward it. As I caught up with her to guide her in the right direction, she quietly said, "Somebody moved the door." At first, I thought she was joking, but her embarrassment revealed otherwise. I had to restructure my thinking.

I reminded myself that Brittany doesn't think visually. She doesn't relate to things according to their positions in space. She receives direction from other sensory cues (in this case, her hearing), which can take precedence over physical memory and logic. I tried to imagine stepping out of that room and seeing what Brittany thought she heard: the exterior of my studio suddenly appearing in front of me, rather than to the right. My initial reaction would be one of confusion, which means I would probably stop and try to rationalize the change by assuming that I had simply turned right and forgotten that I had done so. I wondered, therefore, why Brittany not only didn't hesitate, but how could she so easily believe that the door had been moved?

Then I realized that she doesn't see the exterior of my studio. She doesn't see anything in the context of its surroundings. She sees what she can hear, touch, taste, smell, and surmise. She sees only the smooth hardness of the door frame, and, at that, only the part she touches as she enters the room. To Brittany, that is the entrance: a strip of hard, cool wood no bigger than her palm, with no relation to structural surroundings of sheet rock, carpeting, and ceiling tiles. Her concept of "doorway" is filed in her memory as a kind of infobyte, not as a mental photograph of a door in some recognizable three-dimensional space. She heard a familiar sound, correctly interpreted it as "a doorway," and, in the absence of any conflicting or affirming information, determined it to be "the" doorway.

Try this experiment. Stand a subject blindfolded in front of a ticking timer. Silence the ticking, then have the subject turn around three times, and walk toward the timer. While he is turning, circle the timer's position 1/4 of the way around the subject in either direction. When he stops, restart the ticking. As he accurately walks toward it's original location, he will assume
that he is wrong and change directions. That's how Brittany navigates. If the subject were tested without the blindfold, it would be obvious to him that you moved the timer, and he would not make the mistake of starting off in the wrong direction. Brittany, however, cannot remove her blindfold. She expects doorways and timers to stand still.

Not even buildings stand still in this visual sensory world we have created. We have become so inured to our sensory vision that we must constantly invent new ways to keep it busy and entertained. We have also devised ways to take advantage of it for our better convenience: electronic signals instead of traffic cops, steps instead of hills, film instead of personal experience and memory, printed words and musical notation instead of live communication. All such creations are appropriate and economical to the majority of the population; but without accommodation Brittany would be lost. She has sight and vision. If she is also blind, we are part of the reason.

How are we doing?

Our grade is improving in the area of accommodation, especially since the passing of the Americans With Disabilities Act. Electronic birds chirp at us when it's safe to cross the street. Hills have returned in the form of ramps. We have descriptive movies, audio books, Braille, text-to-speech technology, personal satellite guidance systems, and even gadgets that beep when our coffee cup is full. We probably deserve at least a B for effort, as (admittedly, motivated mostly by financial gain) we develop new and better ways to help Brittany live in our ultra-ophthalmic world.

We are not yet, however, scoring well in Social Development. We don't work and play well with Brittany, because we keep defining her as a blind person. We call her "special," which is short for "different-in-a-way-that-we-don't-understand-so-let-someone-else-deal-with-her-who-won't-screw-things-up-like-we-probably-would." Really, who is the blind person here?

At the age of five, I had a playmate named Karen, who was blinded by an accident with a glass bottle. We used to play one-sided hide-and-seek, where I would hide simply by standing quietly. She was very good at it, and we greatly enjoyed our game until my parents saw what I was doing and made me stop.

"It isn't nice to tease a blind person," they said.

"She isn't blind," I argued. "She always finds me."

They told me I didn't understand, and that was the end of it. So, until her death a few months later, Karen went back to hugging stuffed toys with no sharp points, and I found other playmates. For a while there, Karen could actually see me. Then they made her special, and we were both blind.
So here are ten ways that we can work and play better with Brittany:
1. Try to spend a whole hour with her without thinking about her eyes.
2. Relate to her, not to her condition.
3. Imagine ourselves in her shoes, but don't pity her for having to wear them.
4. Respect the abilities she has that surpass ours.
5. Praise her when she sees, and encourage her to keep looking.
6. Nurture her vision.
7. Maintain an honest heart, because she can see that clearly.
8. Remember that her only handicap is our ignorance.
9. Applaud her for succeeding the hard way.
10. Don't identify her as a blind person.

Don't identify her as a blind person? Then how can we identify her in terms of her ophthalmic condition? That's a fair question, because sometimes such physiological identification is necessary. Brittany is a person with congenital anophthalmia: an "anophthalmiac," or one who is "anophthalmic." Those are specific labels that work very well, because they state an impersonal fact, allowing Brittany the freedom to create her own additional personae. If she is an anophthalmiac who is also blind (cf Question 5), then that, at least, is not a presumption laid upon her by others.

Of course, "blind" is still an appropriate description when the speaker and the listener understand the term in the sole context of Brittany's ophthalmic condition (eg. a discussion between two of her doctors); otherwise, clarification is necessary. For example: "Brittany is blind to light," or "Brittany is light-blind." Still, the more accurate and economical choice is "Brittany is anophthalmic."

The ultimate consideration is not so much the semantics of the word "blind," as it is the connotation. Our understanding and how we demonstrate that understanding is what is important. Our thinking needs to be carefully and sensitively geared, because it guides our actions; and our actions affect how well we relate to others.

Brittany is anophthalmic, but her only handicap is a society that limits her by its own ignorance and failures. She has much to teach us. Let's hope we're not too blind to learn.
Learning to Live With Low Vision:
One Man's Journey Through Rehabilitation

This is a dramatization of the experiences of Jim, a fictional participant in a low vision rehabilitation program. The intent is to introduce the reader to as many of the varied types of tests and interventions as possible. For simplicity, a single character has been used to show many possible approaches. It does not, therefore, necessarily represent a typical case.

Since individual programs will be geared to each person's unique capabilities and goals, evaluation and training may be expected to include some, but not all of the options presented here.

Jim's Story

I noticed it after my last class on a Friday. While writing Monday's assignment on the board, I got some chalk in my right eye. I closed it for a second and couldn't see the letters I'd just written. I actually thought I'd accidentally erased them. That's what it looked like. Like I'd smudged them out with my hand or something. Then I opened my other eye, and the letters were there again.

I thought maybe there was a smear on my glasses, so I took them off. But that smudge was still there, right in the middle of my left eye. And when I looked at the frame around the board, it was all out of shape...distorted. I don't know why I hadn't noticed it before. I couldn't blink that spot away, or rub it away, or anything. It was just there, and I didn't know what was going on.

I was supposed to attend a staff meeting that afternoon, but I didn't. I just left. I had to find out what was going on, so I went straight home and called my optometrist. He made time for me that afternoon. To make a long story short, I knew in a few hours that I had an eye disease I never heard of and couldn't even pronounce. I had become one of the vision-impaired, and I was off on a trip I had never in my life expected to take.

This essay will take you with me as I retrace that journey. It will show you how a program of low vision rehabilitation training can help you to live successfully with sight loss. My hope is that, by having this information early on, you will not have to experience the emotional distress and sense of helplessness that I did when I first faced a future with vision impairment.
What Is Vision Impairment?

An estimated fourteen million Americans are vision-impaired, but only about 120,000 are classified as “totally blind.” This means that a very large percentage of those millions can benefit from low vision rehabilitation.

With the population growing older and living longer, the total number of vision-impaired people is dramatically increasing. Some 2.5 million patients, for example, are newly-diagnosed each year with macular degeneration, a yet incurable disease of the retina that is the leading cause of vision loss in senior citizens. This is serious, not only on a personal level, but for society as a whole. Each year, the vision-impaired community costs the United States more than 22 billion dollars in education expenses, income loss, services, and government disability programs.

An obvious solution to the problem would be a cure for retinal disease coupled with ways to restore lost sight. These developments will be a reality in the future, but until then, the most effective approach has proven to be education and training for the vision-impaired through good rehabilitation programs.

Vision impairment is generally any interference with sight that hinders the performance of daily activities. More specifically, vision impairment is a term which describes varying degrees of vision loss caused by disease, trauma, or a congenital disorder.

Vision impairment may appear as one or more of six general conditions:

- Blurriness, where visual acuity with best spectacle correction is still reduced or blurred;
- Narrowing of peripheral or side vision
- Defects within the field of vision, such as distortion, blind spots, loss of contrast, sensitivity to glare or light, or loss of color perception.

The term “vision-impaired” should not be confused with the term “legally blind.” Legal blindness is defined as acuity of 20/200 or worse in the better eye with correction, or a visual field of 20° or less in the better eye.

A person who meets one of these criteria might still have usable vision, but he would not be able to read without training on an assistive device. Also, he would not be able to meet the requirements for obtaining a driver’s license. This person would be described as vision-impaired, but another person who is vision-impaired may not necessarily be legally blind.

Strategies for individuals with total blindness must be non-visual. Many times, vision-impaired individuals will also benefit from non-visual solutions for improved accuracy and efficiency with a variety of tasks. The worse the
vision, the greater will be the reliance on non-visual techniques and devices.

With diseases that affect the peripheral, or side field, mobility is more seriously affected. Glaucoma, retinitis pigmentosa, and stroke, for example can constrict the visual field to as little as 10 to 15 degrees. Even with this severe limitation, however, rehabilitation can successfully reinforce the individual with training in the use of low vision devices.

**What Is Low Vision Rehabilitation?**

Low vision rehabilitation is like physical therapy for someone who has lost a limb. Its purpose is to develop strategies to maximize or substitute for diminished sight in order to maintain independence and a sense of self-worth. This rebuilding and reinforcement of the visual foundation is accomplished through identification of goals, introduction to assistive devices, and training.

Rehabilitation is not just an introduction to low vision devices. Actually, that may not occur until some time into the program, after the patient has gone through evaluation and training. Only then can appropriate recommendations for low vision devices be made.

Depending upon the patient’s needs, a good program might also provide education, support groups, and individual counseling. It would help the patient to realize that using such devices and techniques is a sign of tenacity and courage, not weakness or defeat.

People with a constricted visual field might expect to be introduced to scanning therapy and devices such as visual field awareness prisms and reverse telescopes. People with severe vision loss should expect to receive orientation and mobility training, occupational therapy, and information about animal guides and occupational therapy.

In addition to these skills, vision rehabilitation specialists teach how to manage daily activities such as:

- adapting the home for safety and navigation;
- improving lighting conditions;
- preparing meals;
- labeling medications, clothing, and appliances;
- writing;
- keeping financial records;
- personal grooming;
- using magnifiers for easier reading; and
- systematizing shopping and payment at the register.
Why Did I Need Low Vision Rehabilitation?

There are some very good reasons for low vision rehabilitation training, the most important being increased physical and psychological health. Research has shown that people with low vision tend to have more emotional difficulties and a higher risk of accidents than normally-sighted individuals. Patients who have undergone rehabilitation, however, have reported significant improvements in their functional abilities, a high rate of continued use of low vision devices, improvement in reading and distance vision, and general satisfaction with the quality of life.

When my right eye went bad, I couldn’t read, and I couldn’t drive. I couldn’t work in my wood shop, which bothered me a lot. I thought I was going totally blind. I became very depressed, and pretty much decided that life as I had known it was pretty much over.

There was more stress at home. The family couldn’t accept the fact that I couldn’t see well, and I just couldn’t help out, couldn’t do the carpentry, and couldn't help my kids with building their houses. My wife, Marie, was very understanding, but it was difficult for her.

I tried to continue teaching. The students and staff were very supportive in the beginning, but they seemed to forget after a while. Writing lesson plans and grading papers was difficult. I particularly had problems with reading textbooks and journals.

Step #1: Evaluation

The first step in the rehabilitation process is working one-on-one with a counselor or specialist who will assess your needs and identify which programs are best suited to meet them.

My eye doctor referred me to the optometrist at the low vision clinic for evaluation. After my appointment was scheduled, a low vision therapist called me and asked me questions about my health, eye condition, and what she called my visual goals—the things I wanted to do, but couldn’t, because of my impairment.

Then, when Marie and I went to the clinic, the therapist talked with us about the problems I had that were caused by my poor vision. She explained how I could make the best use of my remaining sight through training, low vision devices, and services.

She said that together, she, the low vision team, and I would lay out a rehabilitation plan to help me meet my goals, and that my doctors would get reports as we went along. She told me that the program could take
several visits over a few weeks, and that I would have to really want to succeed for it to work. Well, I did want to succeed—not just for myself, but for Marie and the kids—so I said, “Go for it.”

My initial visit was not what I expected. Rather than the kind of eye exam I had received from my medical eye doctor, the therapist put me through a battery of questions and tests to determine my functional needs, my visual capabilities and limitations, and any history of health problems and related treatment requirements that might affect my visual recovery.

Together, we developed a complete case history to determine how I was functioning and what my needs might be. This included an analysis of my reading habits and other near-vision activities, use of low vision devices, and incidents of eye strain or fatigue.

I had to answer many questions about such things as my ability to care for myself, the nature of my home environment, problems caused by my vision impairment, my employment situation, my relationships with family and friends, ways in which I have adapted to vision loss, and how well I’m doing mentally and emotionally.

I thought the questions would never end, but I knew how important they were. The rehab therapist didn’t leave any stones unturned, that’s for sure. I think, by the time she was through, she probably knew more about me than my own wife, and after 36 years of marriage, that’s saying a lot.

After analyzing the results of my initial evaluation, the vision team agreed that I was a good candidate for success through rehabilitation, and they began to devise a plan to fit my needs and goals.

Step #2: Vision Assessment

The next step was for the low vision optometrist to assess my visual functions through tests and techniques which were adapted to fit my visual impairment.

My visual acuity and refractive status were tested using special low vision refractive techniques. These tests made use of larger-than-usual testing charts, control of illumination, the use of trial frame refraction, and techniques that allow for eccentric, or off-center, viewing. The tester also used:

• an Amsler grid, a simple way to identify defects in my central visual field;
• a contrast sensitivity test to determine my ability to discriminate subtle changes in vision that occur in the real world, rather than the absolute black-on-white contrast of visual acuity charts;
• a brightness acuity tester, or BAT, to look at the impact of glare on my retina;
• a color vision test for possible functional implications.
• an ocular motility evaluation to determine if I had any problems with impaired eye movement.
• a visual field test to predict how I might function in day-to-day activities and how well I might respond to various rehabilitative approaches. Four types of visual field tests are available for this purpose:
  1. A tangent screen test, during which the patient identifies a spot of light moving into his peripheral field.
  2. A confrontations test, wherein the doctor introduces objects such as fingers or lights from the side to see if there are any large field defects like loss of side vision to one side due to stroke. This test is not sensitive to small or slight changes in the vision.
  3. A perimeters test, wherein lights or other targets are presented to the patient in various positions. In a manual perimeters test, the doctor controls the target movement and speed of the target and maps out the field loss areas.
  4. A computerized perimeters test, wherein a computer program presents a specific pattern of lights and then prints out the results with analysis.

Finally, to ensure that there were no other ocular diseases or complications, I was given an external eye health evaluation, my eyes were tested for intraocular pressures and also were dilated for an internal examination.

My test results confirmed that I had the exudative, or wet, form of macular degeneration with no other ocular complications. My condition had been first diagnosed as age-related macular degeneration at age 60. At that time, I had large and numerous deposits, called drusen, beneath the retina of both eyes, and my vision was distorted by the accumulation of this debris.

Two years later, at age 62, hemorrhaging developed in my left eye. It was treated with laser coagulation therapy, which stopped the bleeding, but left permanent dark spots in my visual field. My acuity in that eye was measured at 20/200.

A few months after that, hemorrhaging occurred in my right eye beneath the fovea, or the very center of the macula. Because of the location of the leaking vessel, it could not be lasered, so scarring from the bleeding left
that eye centrally blind. Unfortunately, current treatments which might have saved my sight were not available at that time.

Step #3: Rehabilitation Training

I agreed to attend weekly training at the center. My rehabilitation therapist and I established a list of personal visual goals that would give direction to my training. These goals were in the areas of activities of daily living (often called independent living skills), computer use, and counseling. Vocational rehabilitation might have been part of the program, but I was fortunate. Before my rehabilitation training began, I was able to retire early with full benefits. If I had needed to remain employed, several psychometric assessments would have been made to evaluate my current skills as they related to my teaching assignment or other areas of interest.

My training began with safe cooking strategies, labeling techniques, use of adaptive equipment, and an evaluation of the safety and lighting in my home. Most of the training took place in a supervised program of self-care using a specially-designed apartment at the center.

With the help of Marie, who handled most of the domestic responsibilities at home, my level of visual functioning was determined to be safe and sufficiently functional to support my daily living activities. I was trained and evaluated specifically in every important facet of daily living. If my disease was the type that might lead to severe to total vision loss, I would have practiced while wearing a sleep shade. Fortunately, macular degeneration leaves the peripheral field intact, so this was not necessary.

I relearned everything. Things I had been doing my whole life I had to learn to do all over again, this time without depending so much on my eyesight. It wasn’t easy. I trained twice a week for six weeks, and each session lasted for one or two hours.

The first thing the therapist showed me was a system for recording phone numbers, and she enrolled me in the free phone service for visually-impaired people.

Then she showed me how to take care of my clothing and do the laundry in a whole different way. We labeled my clothing and all the appliances in several ways. Sometimes we just used large print, but she also showed me how to use some stuff that left a raised, high contrast line I could feel.

I learned how to sew and iron safely, including how to use a needle threader. And the therapist offered some good practical advice like wearing wrinkle-free clothes. I hate to iron, so that was a very good suggestion.
We got into personal grooming and hygiene, like brushing my teeth and taking care of my finger and toe nails. I never thought how tricky those things could be without good vision.

We worked on budgeting, including using a CCTV and a signature template for reading and paying bills. And now I carry a multi-compartment wallet for keeping my money denominations separate. That was a great idea.

My therapist had lots of good housekeeping tips, like assigning definite locations for cleaning equipment and tools, using disposable plates and utensils, and all kinds of things like that.

She taught me some practical eating skills, too, so I wouldn’t embarrass myself or Marie in a restaurant. I never thought I could use my fingers to eat with and still look classy.

I learned how to cook without burning the house down or losing a finger. I learned to take along a large-print grocery list and a hand magnifier when I go shopping. And one of the most important things she made sure I knew was where our basic medical supplies are and how to identify and use them.

The rehab therapist also worked with me in communications using large print, and in touch typing. I never could type without looking at the keys, but I’m pretty darned good now. They also got me two pairs of sun shields: one pair to cut down glare from artificial lighting, and another for bright sunlight.

I knew how to use a computer already, but I didn’t know about all of the magnification and speech software there is for the vision-impaired. During my residential training, the adaptive technology manager showed Marie and me the latest technology and let us try several different programs. I also know about several agencies and organizations where I can get adaptive software at no cost. Since I’m on retirement income now, that’s good to know.

My condition was not severe enough to require orientation and mobility training. A person with nearly total vision loss would require about 25 hours of individualized sessions by an O&M specialist, with advanced training in actual public situations. The activity would also include several hours of calisthenics and walking. Skills such as safe street crossings, negotiating stairs and curbs, and utilizing public transportation would be learned, in addition to familiarization with new environments. Use of an animal guide would also be an important consideration, as would training in Braille.

Both personal adjustment counseling and marital counseling were undertaken to help my family and me deal with my loss of vision.
Counseling was a daily part of the team approach to my visual rehabilitation.

In general, I handled my vision loss well. The most difficult part was dealing with the changed dynamics within my family and with problems of communication with my children. Gradually, my self-esteem and confidence in my ability to overcome my vision impairment greatly improved.

During my training, weekly team meetings were held, with Marie in attendance. My progress was discussed, and program plans were reviewed. Direct lines of communication were constantly maintained between the rehabilitation center’s staff, the state sponsoring agency, my family, and me.

Low vision management was another important part of my rehabilitation. This centered around two areas: modification of my environment and possible treatment options with low vision devices.

Step #4: Environmental Modification

For patients with mild vision loss, simple environmental modifications may be enough to perform daily living tasks. Patients like me, with moderate to severe visual loss, will also benefit from environmental modifications, but we also need low vision devices to help maximize our vision.

Four factors were taken into consideration when analyzing my home: illumination, glare, contrast, and figure-ground perception.

Illumination

Lighting is probably the most important aspect of the environment for a vision-impaired person. It is also the easiest to modify.

Because of my vision impairment, I needed more light than normal. This was accomplished by increasing the number and power of the lamps and fixtures. For general lighting, floodlights and walkway lights were installed on the outside of the house. For near-vision tasks, gooseneck and swing-arm lamps with insulated reflector shades were placed at all work stations and reading chairs. Different types of bulbs (soft white, clear, etc.) were experimented with to decide which tints were more comfortable for me.

Glare

Next, the rehabilitation therapist helped me to identify potential sources of glare in my home. In just a few hours, they found and eliminated many areas of so-called “discomfort glare.” With Marie’s help and input, shades were added to windows on the sunny side of the house, scatter rugs were
secured to the polished wood floor in the dining room, and I made cutout line guide for reading magazines with glossy pages.

I also keep my brimmed hat and my tinted and polarized glasses handy for any other situations that might occur, either indoors or out. These items are also helpful for occasions when veiling glare makes seeing difficult. Veiling glare is caused by scattering of light within the eye itself, which can result from high-intensity headlights and reflections from the sun in environments over which I have no control.

My retinal condition caused me to be photosensitive, even in lighting conditions that most people would consider to be normal. If my condition was such that my vision was even more seriously hampered by light, my specialist might have recommended soft contact lenses with central red or amber filters. As it stood, however, the changes made by my rehabilitation therapist went a long way toward improving my visual capabilities.

Contrast

Contrast makes it possible to differentiate an image from its background. It is very important to good vision. My rehabilitation therapist found many ways to enhance the contrast of my surroundings, which proved to be very helpful.

The changes they made in my home were simple, but effective. They included:

• Installing faceplates on electrical switches and outlets in contrasting color to the wall;
• Covering a glass-topped table with a dark-colored tablecloth;
• Applying dark-colored decals to a sliding glass door;
• Laying a dark-colored bath mat over the edge of the tub and placing a rubber ball in the bathtub to help me see the water level;
• Wrapping rings of bright tape around handles of pots, tools, and utensils; and
• Applying white paint to the leading edge of the porch steps.

Finally, the rehabilitation therapist had a look at my wood shop. She found my project table to be a victim of "figure ground" or "visual clutter."

Simply put, it required organization so that I could find what I needed without being visually confused by a number of other objects. The therapist also recommended painting the table top a solid, non-glossy light color to make it even easier to locate parts and pieces.
The therapist complimented me on already having my tools fairly-well organized on peg boards, and smaller items, such as nails and screws separated into drawers for easy identification.

Step #5: Low Vision Devices

Magnification of both near and distant images can improve visual function in nearly all patients with central vision loss. I was amazed at the variety of low vision devices that could help me to maximize my sight.

Back at the center, I was given hands-on experience on almost every kind of device imaginable. This included:

- typical optical aids, such as prescription magnification or microscopic glasses
- filters to reduce glare and increase contrast
- hand magnifiers
- stand magnifiers
- head-worn magnifiers
- hand-held and glasses-mounted telescopic systems
- electronic magnification, such as closed circuit televisions

I was also shown typical non-optical aids available from stores and catalogs, including bold tipped pens, large print books and magazines, talking books, check writing guides, talking watches, clocks, and scales, lighting instruments, and book holders.

I was especially impressed with a scanner that could be combined with computer software to read printed text aloud. Nowadays, those are combined into single units called "optical character recognition" (OCR) devices.

I was computer-literate, having used one for years in my teaching. But I had no idea this kind of technology was so easily available to me.

As a result of rehabilitation, I eventually found the low vision devices most suitable to my needs. Then came careful training in the correct usage of the devices. The adaptive technologist gave me large-print instruction sheets to take home, and I was grateful that she didn’t expect me to remember every detail.

The purpose of low vision devices is to maximize sight. This is done through magnification for people who have central vision loss like I do, and field expansion for people who have peripheral vision loss.

A doctor who specializes in low vision knows about the different types of magnification and the circumstances in which each is used. In other words,
when to use angular magnification (such as a telescope or bioptic eye wear), rather than relative distance magnification (such as a hand-held magnifier). Or when to use relative size magnification (such as large print), rather than projection magnification (such as a closed circuit television).

The specialists at the center keep up on the latest technology, so I knew that I was receiving the best information and training available for my unique needs.

In order to select the most appropriate low vision devices, the specialists had to:

- Identify exactly what tasks I wanted to accomplish.
- Analyze my fine and gross motor skills to confirm my ability to operate the low vision devices.
- Determine which of my eyes was dominant.
- Determine whether I would do best with monocular or binocular vision.
- Determine whether I could learn to enhance my vision in a new healthier area of my retina, called the “preferred retinal loci,” or PRL.
- Determine whether my need for higher-than-normal lighting levels would require illuminated magnifiers.

They figured out exactly what I need to see better and to live an almost normal life again. For closeup viewing, they gave me an illuminated handheld magnifier and a stand magnifier.

For reading, which I thought I’d never get to do again, I got a basic tabletop CCTV. It has a magnification range that fits my acuity. That was good thinking.

For my computer I got large-print, white-on-black labels for the keys. I got a scanner with screen reader software, a new 19-inch monitor, software that magnifies the screen and the cursor, and now that machine can even recognize my voice and type for me.

As if that wasn’t enough, my optometrist fitted me with prescription lenses just for using the computer, and they’re tinted specially to take care of eye strain. Then they gave me a little telescope for reading street signs, identifying people, and seeing the sights. It took some practice getting used to it, but it’s worth it.

There are all kinds of what they call non-optical devices, too. Marie and the kids went shopping for my birthday out of one of those catalogs, and I actually use everything I got. Even stuff I didn’t know I needed, like a talking watch. And a gadget that actually tells me when my cup is getting
full so I don’t pour coffee all over the table any more. I can’t wait until Christmas now.

**Finding a Low Vision Rehabilitation Center**

I was fortunate to have an outstanding rehabilitation center near my home. The center offered comprehensive programs with teams of occupational therapists trained in visual rehabilitation, vocational rehabilitation counselors, vision rehabilitation therapists, orientation and mobility specialists, psychologists, assistive technology computer specialists and other professionals as needs dictate.

Such teams can be found in some university centers and large private clinics. Rehabilitation services may also be provided by charitable organizations such as Lighthouse Guild in New York City, Alphapointe Association for the Blind in Kansas City, and the St. Louis Society for the Blind. The VICTORS program under the Veterans Administration is an excellent regional rehabilitation service for veterans.

All state governments in the United States fund an agency to coordinate the visual rehabilitation of its vision-impaired citizens. They take care of most of the rehabilitative efforts, either directly or through subcontractors. These services are called either “Rehabilitation Services for the Blind” or “Commissions for the Blind”.

In cases where a person might not meet the eligibility requirements of the state blindness agency, but the person’s employment is being adversely affected, they can go for help to the state’s vocational rehabilitation agency.

**Paying for Low Vision Rehabilitation**

How did I get the help I needed, and how was it paid for? The referral mechanism differs slightly with each state, but generally, a referral can be requested by any individual, family, friend, eye care professional, rehabilitation specialist, or social worker.

State statutes specify the minimum levels of vision loss for entry into the program, but there is also some flexibility in the acceptance standards. A doctor must provide documentation of the best-corrected visual acuity and/ or the visual field in each of the patient’s eyes.

State agencies will usually cover the costs of rehabilitation for people who are registered. Those who are not qualified for government assistance might expect to pay their own expenses.

Government agencies do the best they can with the limited funds available, and private or non-profit organizations help to fill the gap. The task, however, is much larger than current budgets and resources allow.
According to the Alliance for Aging Research, vision impairment is one of the four leading causes of lost independence among older people, with annual costs for medical and long term care in the billions of dollars. Low vision rehabilitation can cut these costs considerably by helping to restore functional abilities, safety, and independence.

Conclusion

Since my initial low vision assessment and training, I have greatly improved my skills for independent functioning. My social life has slowed somewhat, not so much because of my vision impairment, but because of my retirement from the school system. Marie and I still go out when our budget allows, and we enjoy the closeness and support of our active family.

Vision rehabilitation isn’t easy, and it isn’t a cure for blindness. It’s an educational process that requires patience, practice, flexibility, and motivation. And it requires a team of professionals who know what they’re doing and who care about you as an individual.

The specialists and doctors at my rehab center were good, but they could be only as good as I would let them be. As I always told my students, if a person doesn’t have a real reason to want to learn—a ton of self-motivation—then there isn’t anyone who is going to be able to teach them.

It was a long road, but I don’t even want to think how long the rest of this road would be without the confidence and independence those people have given me. They gave me the tools, taught me how to use them, and showed me that my life can be just as good as it always was. Different, maybe—not like I thought it was going to be—but it’s good.

________________________________

Credits

Author: Dan Roberts

Consultants:
• Brian Gerritsen, M.A., CLVT (Rehabilitation Specialist, Low Vision Rehabilitation Services, North Ogden, UT)
• Joseph Maino, O.D., F.A.A.O. (Chief, VICTORS Low Vision Rehabilitation Program, Kansas City VA Medical Center)
• Clay Berry (Assistant Director of Rehabilitation, Alphapointe Center for Blindness and Low Vision, Kansas City, MO)
Information sources:
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• L. David Ormerod, MD, Sue Mussatt, RN, and Associates (authors: Low Vision Assessment and Rehabilitation, School of Health Professions and School of Medicine, University of Missouri, Columbia)
• University of Iowa Center for Macular Degeneration
Loss of Confidence
A Message to the AMD Community
1998

I have experienced a symptom of vision loss, and I wonder if anyone else can relate to it. It is not physical, and it is not emotional. This is a much more subtle psychological symptom which seems to lurk in the background and affect nearly everything I do.

My wife, Chris, has been trying to get me to fix our refrigerator’s ice maker for months. This would normally have been a welcome challenge to me, but after a feeble attempt which took much too long, I gave up.

Our porch light developed an electrical short. A project which used to take me only a few minutes used up nearly an hour, and my half-hearted repair will probably not last.

I am frequently invited to do acting workshops for schools and businesses—something at which I have always been successful. But a session which I did two weeks ago kept me awake all of the previous night wondering if I was going to ruin a hard-earned reputation.

I have been rationalizing this new personality of mine with thoughts like “I don’t have the time,” “I don’t need to prove myself,” and “I’m semi-retired, so I don’t have to work so hard.” Then, last Monday, I began to admit the real truth: that I am starting to give in to my slowly-decreasing vision. I am losing my self-confidence.

It started when I went to the computer store with Chris. I had not been in that store in quite a while, and it all looked slightly different to me. Everything was more askew and unfocused than the last time, and I had trouble reading the displays on my favorite software racks. I displaced my frustration with surliness, and Chris (bless her heart) decided to not take it personally.

When we left, and I got into the driver’s seat (I still have one eye which allows me to do that), I was feeling a little shaky. Of course, I didn’t tell Chris, because she already worries about whether or not I am fully capable of driving safely; and if I were to admit my nervousness, that would only concern her further. Anyway, I had already lost some Brownie points with her earlier by narrowly missing a concrete divider in the parking lot.

I needed to go to a computer store on the other side of town, and Chris had other things to do, so I dropped her off at home. She offered to go with me, but I told her it was not necessary and set out on my own. This was the first time in a long while that I had driven any real distance without her, and
I felt a twinge of loneliness as I pulled out. Loneliness? What a strange thing to feel, I thought.

Twenty minutes later, I pulled into the parking space at the store. As I got out, I berated myself for parking over the line and too close to the vehicle on my right. I have never understood people who do that, and I considered correcting it before going inside. Deciding, however, that I would probably not do any better the second time, I left the scene of the crime.

The store, of course, did not have the computer hard drive I needed, and the salesman recommended another place west of there. He gave some vague directions, and I headed out. As I drove away, I was immediately disoriented. This made no sense, because I knew the area. So I drove carefully and paid extra-close attention to my surroundings—a totally foreign way of thinking for me.

As I headed west, I avoided the highway. I had driven that stretch a week earlier with only my nine-year-old granddaughter and me in the car. It was dark and raining then, and I worked hard to see through both the distortions on the windshield and the distortions in my eyes. Driving slowly in the right lane, I got us home just fine, but the fear I had experienced then was now flashing back at me, so I took the city street instead.

After a while, I began to wonder if I was going the right direction, so I decided to pull into a convenience store for a phone book. I turned left at the next intersection, into the wrong side of the median, and ended up facing oncoming traffic. They stared at me as if I were some senile old man while I inched my way along, and—thanks to one gracious driver—I was eventually allowed to turn across the lanes into a parking lot.

I phoned the store and was put on hold for ten minutes. Trading my 35 cents for my pride, I finally hung up and decided to push on to the West.

By now, the overcast day had turned into a very bright, cloudless one. I had not brought my sunglasses, and the afternoon sun was shining right through the windshield. I knew that I was going to have to read every street sign along the route, but I also had to drive in the left lane to be ready for my turn. How was I supposed to see those signs? And even worse, how was I supposed to look out for the traffic in that busier lane while I was doing all of that squinting and blinking?

I felt helpless. I considered stopping and calling Chris—something I always promised I would do. But it’s not time for that yet. She would never feel safe with me again, and she would worry even more than usual whenever I go off alone. I still have one pretty good eye, and I’m not ready to give up yet.
Finally, I found the store I was looking for. I followed my nose instead of my eyes, and I was pretty proud of myself. I had set out to buy a hard drive, and that was one of the hardest drives of my life. Pretty funny, huh? Anyway, by the time I had paid for it, I thought, “How am I ever going to install this thing?” Ten years ago, that thought would never have crossed my mind. But something had happened to me, and it was made worse by the past hour. I hated that.

Just to see if I could do it, I took the highway all the way home. I made it. Then I wrote to a friend on the Internet and, thinking that my computer would probably go up in flames and I she would never hear from me again, I said “I’m going to install a hard drive. Good bye.” Well, it took me three hours, but I did it.

Yesterday, Chris asked me if I could replace the posts on our granddaughter’s canopy bed. She was very kind, saying, “But you don’t have to get to it right away.” (She remembered the ice maker and the light switch.) Okay, I got my tools, and those posts are not only in place, but they are almost vertical, by gosh.

On Monday my confidence was gone. By Wednesday, I had it back. That’s all I know. I still haven’t figured out what happened, because I’m still riding the roller coaster. I just want someone else to know that this is happening so that, if it is happening to you, too, we will both know we have company.

I have learned one thing this past week: there is something in me that will try to give up when things get tough. But there is also something in me that gives me strength to do what has to be done. It looks as if I am going to have to keep that in mind from now on.

Now I’m going to go give that ice maker another shot.
Musings on Growing Old

2018

I’ve become an absent-minded, decrepit, sleep-deprived, unfit, anti-social, wrinkled image of my former self.

For one thing, I’m forgetting words mid-sentence. My listeners usually suggest a few words until either they either lose interest or hit upon a good substitute, at which time I forget what I was talking about anyway.

Then there are teenagers’ words. My granddaughter said, “Juicy woodeye rodinyer birdie car?” I told her I think her mouth is set at 78 rpm, while my brain still turns at 45. She said, “What?” . . . End of conversation.

Speaking of food, I’ve lost so many teeth, the only thing I can chew is yogurt. I’d be willing to let a juicy steak melt in my mouth, but I can’t afford the steak . . . or the time.

And sleep. Even if I could sleep more than two hours straight, my incontinence wouldn’t allow it. At least I get twenty-or-so minutes of snooze time on the toilet. Sometimes I doze off riding the stairlift, so that helps, too.

I takes so long going to the next room, I forget why. I could write myself a reminder, but I couldn’t read it even if I could find a notepad. Or a pen that works. Or remember why I’m going to the next room.

I’ve gotten shorter, weaker, and smellier. I think I’m decomposing early.

The only productive exercise I get is when I trim my toenails. I can’t reach my pinky toe, though, so that nail’s just going to have to fall off on its own.

I used to lift weights. Now the only weight lifting I do is when I stand up.

No one calls, no one answers. I would leave a message, but by the time I remember who I’m calling, why I’m calling, and my phone number, I get beeped.

The only times I get out are for weddings and funerals. I don’t mind ceremonies and church services, but receptions make me meshuga. I can’t dance from the waist down, bright lights blind me, alcohol makes me tip over, and cake makes me sleepy. Plus, I can’t hear or understand a word anyone is saying, so I sit silently in the corner wondering things like how I know the word meshuga when I’m not even Jewish.

I remember when I was under-age. No alcohol, no sex, no driving, and no one listened to me. Now I’m over-age. No alcohol, no sex, no driving, and the only time anyone listens to me is through a stethoscope.

I’ve been on the shelf so long, I think I’m reaching my expiration date. Why is my body wrinkled everywhere except where no one can see it? Here are ten things I’ve learned as I’ve grown old:
1. Gravity is not my friend.
2. If I can see well enough to look for my glasses, I’m wearing them.
3. If the walk from someplace is as far as the walk to it, there’s a 50% chance I won’t make it back.
4. Waking up in the same position that I fell asleep doesn’t mean I’m dead.
5. Waking up is usually a good sign.
6. I can save money by not buying extended warranties or 25-year paint and caulk.
7. I can’t come up with ten things I’ve learned.

So with that, my musings end with this little rhyme:

If you’re growing old like me, I know you understand.
If your trek is yet to be, enjoy it while you can.
If your remaining time is long, may you live it in peace.
If your spirit is strong, may your blessings increase.
The Monster Behind The Door
Speech for PBA Awards Banquet
November 2, 2012

Thank you for the privilege of speaking to you this evening, and the opportunity to get to know more of the great people of Prevent Blindness America. I’ve long admired the work of this organization and have referred many of our low vision community members—especially our younger people—to your services and resources over the years.

MD Support focuses principally on the senior population, so a team effort by our organizations makes perfect sense. And I hope we can find ways to do that even more extensively in the future.

When I was a child, there was a monster behind my closet door. Probably the same monster that lurked under your bed or somewhere else in your bedroom. I thought it might be a gorilla, but I never found out, because Mom and Dad slept in the next room, and the gorilla was afraid of big people.

Well, it never did get me, and, as I grew to young adulthood, I didn’t think much about the gorilla, because I was invulnerable, healthy and cocky enough to think I could handle anything and live forever.

But then, when I was 48 years old, a doctor told me I was going to go blind, and there was nothing he could do about it. That’s when my monster shoved open the door, and I recognized it for what it was: The Unknown. It was scarier than a gorilla or anything else I could have imagined. And I was totally defenseless. There was no big person sleeping in the next room who could make it go away.

So I ran. I ran to a place in my head where I could cower and cry and wait for the inevitable. I was a high school teacher in a room with no windows, so I retired early to enjoy looking at the daylight while I still could. I was a theater director and a church music minister who was going to have to try reading scripts and music in dim light. So I retired from those, too.

Then, with all that extra time on my hands, I had plenty of opportunity to think. And the more I thought, the angrier I became. Not at the doctor who told me there wasn’t anything anyone could do for me, but at myself for believing him. Sure, he stepped out of the way and let the gorilla knock me down, but that didn’t mean I couldn’t try to get back up. So my anger gave me strength. And, relying on the support of my wife, Chris (because I wasn’t as alone as I thought), I started figuring out how to make the Unknown known.
We bought a computer and found that thing called the Internet, where I found a few people who understood. And when I started finding answers (not necessarily solutions, but at least answers), and when I had connected to others who were traveling the road with me, I gained more strength and realized that my big scary gorilla was really just a skinny little monkey.

As anyone with progressive vision loss will tell you, it is the fear of the unknown that is so debilitating. But, as Lillian Russell said, “What one does with that fear will make all the difference in the world.” And that makes it one of the biggest challenges we face in coping with progressive vision loss. But, even though we cannot yet beat the disease, with knowledge and human support as our weapons, we can beat the fear it brings.

And that’s where organizations like PBA and MD Support come in. We are the “sentinels at the bridge” between diagnosis and acceptance. We are making the unknown known for untold numbers of frightened patients and caregivers, and how lucky I would have been to have had someone like that.

How I wish someone would have been there when I left the clinic that first time, to tell me I wasn’t going blind. To tell me about things I could do, even if the worst happened, to maintain my independence and quality of life.

Someone who could have introduced me to low vision devices, computer technology, low vision rehabilitation, clinical trials, support groups, government benefits, transportation options, and personal counseling. But no one did. Maybe someone could have talked me out of retiring early by telling me that the progression of my particular disease is usually tracked in years, not days. But no one did.

The sad thing is that there WERE people who could help. Like my state agency. And other organizations and resources to help people like me. Why didn’t I know it? Because no one showed me where to look. In 1997, it wasn’t as easy as doing a Google search. We depended totally upon doctor referrals.

And today, even with the immediacy of the Internet, millions of elder seniors are still unconnected to the information and support that could literally save their lives. Recent polls show that about 40% of seniors are not familiar with Internet technology. And my experience has shown that more than half of that 40% cannot, or will not, take advantage of it. So they still need intermediaries to pull them into the circle, and that means continuing to reach out through clinics, schools, libraries, retirement centers, educational seminars, kiosks in shopping malls, television, radio,
and hopefully through their younger family members who ARE familiar with the Internet.

If I had not heeded Chris’s insistence about searching out the resources, I might be telling a whole different story. But I listened to her. And because of that, I’m okay. But not JUST okay. I have discovered the joy of helping thousands of others through MD Support to understand that this is not a dead end. It’s just a detour. Our lives are still on track. We’re still parts of families and communities, and we still want to find ways to be meaningful. It’s just that we’re traveling a road we didn’t expect.

We set out in life with a vision of a straight, smoothly paved road along which we plan to travel unhindered into the future. But sometimes barriers block the way. We then have a choice to either stop, or turn back, or we can shoulder our bags and take the detours. And that can take us in some very interesting directions. And when we do get back to the main road, our bags will be a little heavier with the stuff we’ve picked up: souvenirs, hitchhikers, treasures, even some trash. It’s all in there, and good or bad, it’s a unique collection.

So far, my bag contains memories of people I never would have met if I had stopped on the main road.

And, oh, the people I’ve met . . .

Donna: The first person that welcomed me. She called herself the “Older’n’dirt Lady”, and in spite of her advanced MD and severe COPD, she never failed to make me laugh and to give totally of herself to everyone she met until she died of pneumonia in 2003.

Bob: A 92-year-old former World War One Royal Air Force pilot who lived in Australia with two cockatoos and hallucinated naked ladies on the wall of his bedroom every morning. That was a result of Charles Bonnet syndrome, which he insisted he didn’t want to be cured of.

Gideon: A man with advanced AMD in his mid 70’s, founded a successful low vision organization in Israel. We have since become close friends, in spite of having met in person only twice.

Joe: Who was diagnosed at age 70, and set about learning and teaching the art of digital photography to prove that nothing is impossible for people who are willing to learn and adapt.

Kimber: A teenager with Stargardt disease who won state equestrian championships and now teaches others how to show and ride horses.

Tabby: Who finally convinced her parents at age 12 that she was visually impaired. She has since used that same tenacity to earn a degree in law from Harvard.
Tom: A retired priest who showed me early on that even someone with severe visual impairment could live independently in Manhattan and take Chris and me on a sightseeing tour.

These are only a handful of thousands of people in my bag, and, if I have learned only one thing from all of them, it’s that life challenges us over and again. And as we pass each test, overcome each obstacle, and confront each challenge, we become stronger. But only if we stick together. Because by sticking together, we can’t be worn down.

So, because I took this detour, my bag is full of people I never would have known, experiences I never would have had, places I never would have been, and challenges I never would have confronted. It also contains some moments I would just as soon forget.

Like when I was waiting my turn in the post office and saw Sheila, a fellow teacher, at the counter. It had been over twenty-five years, at that time, since my retirement, but that was Sheila, all right. I couldn’t quite make out her face, but she was talking a blue streak, as usual, to the postal clerk about something or other; and I would know that voice anywhere.

By way of greeting her, I very loudly joked, “You know, if some people weren’t so gabby, the rest of us might get faster service here!” To which I expected good old Sheila to bite back with something like, “And if you weren’t so crotchety, you could have gotten here before me!” Then everyone in line would have had a healthy laugh at our antics, and this particular Monday morning would have become a little brighter.

But she wasn’t Sheila. I don’t know who she was. She just gathered her purse, whispered, “I’m sorry, sir,” and slipped quietly away.

All I know is that my mumbled apology meant zip to her and everyone else in line, and I’ll never again be able to show my face in that post office.

Hopefully, our fear of the unknown, and our fear of making mistakes, will not stop us from taking the detours, because doing so takes courage. And like Dorothy’s Cowardly Lion, we can find that courage when faced with a choice between living well or barely living. And maybe we can even roar a little bit when we have the support of people who are willing to travel the road with us.

That original little group of people I found on the Internet in 1994 grew to several hundred, and, known as MDList, which I eventually took over as owner and moderator, we have been sharing our knowledge, our feelings, and our ideas for almost 15 years now. This has not only been a lifeline for all of us, but we have been able to provide the vision care field with some valuable input from the patients’ perspective.
We have participated in market surveys, focus groups, research studies, and opinion polls. We have participated in FDA committee hearings, congressional briefings, vision summits, and seminars. We have produced educational videos, and we have produced publications such as “A Self-Help Guide to Non-Visual Skills” and a book called “Through Our Eyes”, a collection of our essays and poetry about personal experiences with low vision. Because we are joined together, we have been able to gently roar, and, by doing so, we would like to think we have had a positive effect that will help pave the road for those who will follow us.

Fear of the unknown, and of being alone, are the worst of all fears, and, therefore, the biggest challenges in coping with progressive vision loss. But our questions do have answers, and together we can find them. Likewise, we can find solace in one another when the answers are not what we want to hear.

I would like to close by reading a short message from Anne, a long time member of our Internet community. She wrote:

“Imagine this. You are alone in a small boat on a lake. It’s a perfectly beautiful day, calm, the water is sparkling, and you are taking it all in. Out of nowhere, clouds roll in, heavy and dark. You head for shore, but your boat begins to sink. You slip into the deep, dark, murky water...You thrash about and cry for help.

“You are about to give up when you find that you are being raised from the water and carried to shore. There, beneath you, is a net; but it is not made of rope. It is made of people, and you are being comforted and held firm.

“The net was invisible beneath the surface, but it was there to rise up when you needed it. All you had to do was call out. You were not alone.”

On behalf of millions of people like me, thank you for being our net, and thank you for this opportunity to join with you here this evening.
The retina is the thin lining in the back of the eye, and the macula is at the very center. When the macula is healthy, we are able to see in fine detail. When it isn’t, we can lose the ability to read normal print, drive a vehicle, and recognize faces. The macula comprises only five percent of the retina, but what an important percentage that is.

If you are losing your central vision, you may have age-related wet or dry macular degeneration. You may have one of the juvenile forms, such as Stargardt’s disease or Best disease. You may have angioid streaks, choroideremia, central serous retinopathy, Coat's disease, cystoid macular edema, or myopic macular degeneration. Or you may have any one of a number of other incurable conditions which can cause loss of central vision. If so, then you are one of millions of people who deal daily with the physical and emotional challenges that come with losing vision: the most vital of our five senses.

Scientists say that about eighty percent of our sensory information is obtained through sight. No wonder it is so traumatic when we lose the ability to see well. Normal daily activities like reading the morning paper, pouring coffee, writing checks, watching television, and even getting dressed can become seemingly impossible activities.

As our vision declines, we have basically two options. We can either allow ourselves to become handicapped, or we can find ways to deal with the inevitable problems and live quality lives. That is what this presentation is about: learning to live well with central vision loss.

This presentation will touch upon six important areas related to visual impairment:
1. How to recognize signs of depression, and what to do about it.
2. How to adapt the home and work environment.
3. The rights of the visually-impaired under the Americans with Disabilities Act.
4. How to find important information about assistive devices, computer aids, large print reading materials, audio books, organizations for the visually impaired, and agencies for rehabilitation and assistance.
5. Where to find support from others.
6. How to find information about the research that is being done to combat retinal disease.
Most people experience an emotional reaction when they are first told that they have an incurable retinal disease. Many react in disbelief, or shock, or anger. Others may experience sadness or a sense of loss. And some may think, “Okay, I’ve got something that’s going to make my life more difficult. But it’s not going to kill me, or cause me pain, so I’ll just learn to deal with it.”

Most of us eventually reach that point, but usually not until we have paid an emotional price. We find, however, that, as we begin to adapt, learn about our condition, and share our experiences and feelings with others, our strongest emotions will lessen. Hopefully, those emotions will evolve into a strong determination to not let visual impairment get the best of us. Or worse, beat us. That kind of tenacity is our best defense.

Retinal research is progressing, and breakthroughs are becoming more frequent. A cure for macular disease is going to be found, and there is even hope of someday restoring lost vision. These developments, however, are several years down the road. In the meantime, we may want to maximize our abilities by building a special kind of personal T.A.S.K force.

T= Tenacity
A= Adaptability
S = Support
K = Knowledge

The letters T.A.S.K. stand for the four elements of success for a visually-impaired person.

Tenacity: the determination to explore new directions. We can maintain our quality of life if we are persistent in our search for the tools and resources needed to overcome obstacles—even when we’re told that nothing can be done.

Adaptability: our willingness to change our way of doing things. We had no choice when it came to losing our vision, but we do have choices when it comes to how we are going to live with it.

Support: from which comes “cope-ability”. Family members, friends, and organizations can provide the understanding and assistance we need to cope with low vision.

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

Tenacity

If you are losing your vision, you are probably here to learn ways to continue leading a full and independent life. That means you are squarely facing the possibility of vision loss and showing the tenacity that is the first element in your personal T.A.S.K. force.

The opposite of tenacity is retreat. That can happen when the enemy seems to have the upper hand, and we see no hope of winning. Here is what a woman named Judy wrote about the moment of her diagnosis of wet macular degeneration:

“The surgeon said, ‘We have to perform laser treatment either now or tomorrow first thing. Go have a cup of coffee, take a deep breath, and then come back and tell me what you’ve decided.

“I didn’t drink coffee, but ran outside. I was petrified by the thought that I was well on my way to becoming legally blind. I felt that every step I took would be my last as the person I had always been. My husband caught up with me, and we reviewed my options. It was all coming at me too furiously fast.

“All I could think of was ‘Do I trust my surgeon? Do I trust my husband? Do I trust myself to handle the intense misery I felt, and still go on?’ I was such an emotional wreck that I was not able to make the simple decision whether or not I wanted to drink coffee. All I wanted to do was retreat, and maybe this evil thing would go away.”

Judy did not retreat, but began to search the Internet for information. That’s where she found MD Support. She soon became one of our most valuable volunteers, guiding thousands to the resources they need.

Others working for the cause of public awareness have included:

• Gideon, who started a support organization in Israel.
• Frances, who ran a support group in Nevada and who appeared on television talk shows to discuss macular degeneration.
• Linda, who developed her own web site, responding to email messages from anyone who wrote for help.

These people have fought the urge to retreat by directing their energy toward public service. Others have shown their tenacity by simply maintaining their way of life as normally as possible:

• Mary is a property manager.
• Tom runs a ranch in Colorado.
• Dave enjoys boating.
They know how it feels to be diagnosed with an incurable disease of the retina, and they know how important it is to go on in spite of it. They also know that going on is not only possible, but that the very act of tenacity can sometimes reveal strengths which they never knew they had.

The most difficult hurdle for some people is depression. Upon first hearing their diagnosis, many people go through the same kind of grieving process that occurs after the death of a friend or loved one. This is very common and absolutely normal. It is not normal, however, if depression continues for more than a few weeks. That could be serious, and intervention by family members or friends may be necessary.

In the book, “Macular Degeneration: The Complete Guide to Saving and Maximizing Your Sight,” ophthalmologist Lylas Mogk and co-author Marja Mogk list the most common symptoms of depression:

- Frequently feeling apathetic or unmotivated
- Frequently feeling agitated, empty, or numb
- Feeling negatively about yourself or frequently pessimistic
- Withdrawing socially
- Insomnia or hyper-insomnia (that is, sleeping too little or too much)
- Losing or gaining more than five percent of your body weight in a month
- Noticeable decrease in energy
- Unexplained episodes of crying

What causes depression in people who are experiencing sight loss? According to the authors, such a response may arise from:

- Deep feelings of rage, grief, or frustration
- Isolation or loneliness
- Prolonged inactivity or boredom
- Self-judgement
- Fearing the future
- Feeling out of control or without options

You cannot hide or ignore clinical depression. It is a very real psychological condition caused by an imbalance of the brain chemicals which control your emotions. Lylas and Marja Mogk also list some ways to help treat depression.

- Consult a doctor
- Ask about antidepressant medications or alternative treatments which might help you;
• If you are sensitive to sugar, or if alcoholism runs in your family, ask about switching to a balanced carbohydrate-protein diet that is designed to keep your glucose levels stable;
• Begin a regular routine of physical exercise. Along with having other health benefits, exercise acts on the chemicals in your brain to help stabilize moods;
• Attend a visual rehabilitation program;
• Avoid isolation by cultivating your own commitments, activities, interests, and friends;
• Consider using alternate modes of transportation.
• Seek professional counseling to help you express your feelings, focus on your skills, and combat negative thoughts which are self-judging or limiting.

Above all, if you need assistance, ask for it. Don’t be afraid to mention your visual impairment. You’ll be amazed at the number of people who want to help; and they’ll respect your courage and honesty.

If, after a while, people don’t always ask how you are doing, or they don’t offer as much help as they used to, you shouldn’t assume that they have stopped caring. It may be simply that they don’t know what to do. Also, since there is no visible sign of your condition, they are not constantly reminded of your vision, as you are. They may even think that you would prefer to not discuss the subject.

A good sense of humor and an openness about your feelings and needs are usually enough to prevent awkward situations and to help others relate well to you.

Here are some simple rules of etiquette which you have the right to expect in social situations. These “Ten Basic Courtesies” may not all apply to your situation at this time, but they are good for everyone to know.

Ten Basic Courtesies
(by Carl Augusto, President, American Federation for the Blind in New York, and David Mcgown, executive director of the Guild for the Blind in Chicago)

1. Address us by name when possible, so that we know you are talking to us.
2. Speak directly to us, rather than through someone else.
3. Greet us by giving your name so that we recognize you.
4. Speak in a natural conversational tone. It is not necessary to speak loudly or to over-enunciate.
5. Feel free to use words which refer to vision. We also use the words “see,” “look,” “watch,” and so on. And remember, we are not offended by the term “blind.”

6. Be calm and clear about what to do if you see us about to encounter a dangerous situation. Saying “stop,” for example, is better than saying, “watch out.”

7. If you think we need assistance, ask first. Don’t assume that help is needed.

8. When offering assistance, never take hold of us uninvited. Simply make the offer, and let it be our decision.

9. Never take hold of a white cane.

10. Never pet or distract a guide dog while it is on duty.

Tenacity was defined above as “having the determination to explore new directions.” We have seen that the first steps in this journey may require us to:

- Discover and develop our hidden strengths.
- Maintain a sense of humor and an openness about our feelings.
- Avoid depression by focusing our energies on positive action and productive activities.
- Communicate to others our expectations of the basic courtesies which we expect as a visually impaired people.

At the same time, we will want to begin building the other three elements of our T.A.S.K. force: Adaptability, Support, and Knowledge. These elements can, and should, be initiated simultaneously and as soon as possible.

Until a few years ago, that was very difficult to do; but thousands of people are now finding very timely emotional relief, due to the immediacy of the Internet. In the early 90’s, information on the Internet about macular disease was sparse. Also, most people were not yet connected to the Internet. Now, however, everything we need is within easy reach. Every question has an answer, and every answer is a strike against the emotional assault of vision loss.

Adaptability

When first diagnosed, we are told that we might eventually lose some or all of our central vision. Many might think that they will also lose their independence as a result. In all honesty, it is not easy living with central
vision loss; but with a few changes in our environment, and with the help of some assistive devices, we can continue to live full and independent lives.

Even if our condition progresses to its fullest, we are still be able to function with our peripheral vision intact. This means that we are still able to move about unassisted and continue to see the world around us.

We do, however, need to make some adaptations, due to the loss of our fine detail vision. One of our Internet discussion sessions was on this subject. Our featured guest was Dorothy H. Stiefel, executive director of the Texas Association of Retinitis Pigmentosa. She offered what she calls her “common sense tips for every day living,” the first and foremost of which is to slow down. It will take a little longer to finish projects and get where we’re going, so we need to give ourselves the gift of time.

While moving around, either at home or out in public, Mrs. Stiefel advises that we take our time and learn to move carefully to avoid injuring ourselves. In her booklet titled “Retinitis Pigmentosa: Dealing With The Threat Of Loss,” she wrote:

“I tried to keep up my regular brisk pace and managed, instead, to set myself up for disaster. In the grocery store, I have stumbled over boxes in narrow aisles and walked headlong into posts. That was painful, but when I ran shopping carts into posteriors and ankles, it was mortifying.

“So I took myself in hand, and, bearing a grimace, I literally forced myself to move around more carefully. Well, I felt like I was walking in slow motion, so I turned my reduced gait into a dignified, almost matronly stroll—the con artist at work—and transferred my fast-paced energy into other channels of activities less hazardous to life and limb.”

Another good idea that came out of our session with Dorothy pertained to walking outdoors. If you take walks outdoors, wear a hat with a brim or bill for shade, protect your eyes with 100% UV-protective sunglasses, and wear sensible shoes. You might also consider walking during midday for the best lighting and fewest shadows.

You may have heard of glasses called “blue blockers.” They filter out blue light rays, which cause glare and which are thought to be harmful to the eyes of people with retinal cell degeneration. You can purchase UV protective blue blockers from a number of dealers. Be sure to order glasses with top and side shields for the best protection.

You may be able to get around fine without a cane, but it is a good idea to carry one which has been painted white as a universal signal to others that you have a vision impairment. It is nothing to be embarrassed about, and it could help you through some potentially awkward situations.
More Helpful Hints

• Get measuring cups that are individual.
• In your home, doorways never seem to be wide enough, so when approaching them, use the back of your hand to guide yourself through. This will prevent you from possibly hurting your fingers.
• For every day meals, consider using disposable plates, cups, and utensils.
• Put lighting directly on the task at hand. And, for situations where bright light is needed, use tungsten halogen lamps. They provide the widest spectrum of color for best vision.
• Be sure to keep your dishwasher and cabinets closed.
• Avoid scatter rugs, which can cause tripping.
• Pick specific places for items, and train family members to put them back. Be organized to keep rooms free of clutter.
• Keep dining room chairs pushed in.
• When moving from one place to another, a basket is good for keeping necessary items handy, such as magnifiers and flashlights.
• Learn to use your hands and fingers to feel what you used to do by sight.
• A small telescope is good for finding things other people have moved, and it is great for seeing details and reading signs outdoors.
• Buy a coffee table with rounded corners.
• For sewing, use a needle threader or self-threading needles which you can buy in a kit.
• Drag your laundry in a bag. It’s easier and safer than carrying.
• Buy clothes that are color-coordinated, but then mix and match.
• You can mark the colors on your clothing and shoes with a product called “Puff Paint.” It’s raised, washable, and you can design certain symbols for certain colors.
• Of course, you can always buy same-colored socks that can be matched easily.
• And it’s a good idea to have someone who will tell you when you have stains on your clothes or other such problems.

These are just a few of the tips shared by our MD Support discussion group, and it seems that, when we put our heads together, there is no end to the possibilities for making our lives easier.
Low Vision Devices

You can buy such things as talking clocks and watches, sewing machine magnifiers, and needle threaders. They even sell a portable liquid level indicator that signals when your coffee or soup is reaching the brim. And you can buy magnifying mirrors, hand-held magnifiers, phones with large buttons that light up, large-print playing cards, binocular glasses, and talking scales, to name just a few of the low vision products on the market.

A good purchase might be an electronic desktop magnifier, formerly called a closed circuit television (CCTV). With this, you can project greatly-magnified images of printed matter onto a monitor or television screen. Several models are available, with brand names such as Aladdin, Video Eye, Magni-Cam, and Max, to name a few.

What works for one person may not work as well for another, and electronic desktop magnifiers can be expensive, so you will want to try several models before purchasing. A low vision optometrist or a rehabilitation specialist can help you, so ask your doctor to recommend one in your area, or contact your state agency for the blind.

Enlarged print

If you are still able to see to read, but you find normal-sized print to be a problem, you can easily find materials which are available in large font. The Library of Congress offers Braille and recorded books and magazines on free loan through the mail to anyone with visual or physical disabilities. The National Association For Visually Handicapped also runs a free loan service, as does the National Library Service for the Blind and Physically Handicapped. Canadians can take advantage of the National Library of Canada Large Print Publishing Program or the CNIB Library for the Blind.

The New York Times offers the news in 16-point font, called the Large Type Weekly, and Reader’s Digest also offers a large-print version of their publication. Most major publishers create large print editions when demand justifies the expense. Amazon.com currently lists more than 22,000 such publications now on the market. If, however, a title you want is not published in large print, there are companies that, for a fee, will either reprint it for you or download it to your computer so that you can read it using magnification software.

MD Support’s resources contain dealer information about these publishers, in addition to more than one hundred booksellers around the world who deal specifically in large print titles.

If you own a computer and a scanner, you can enlarge printed material yourself on your monitor screen. A scanner will convert the printed material
into a computer file, which you can then open and magnify to any size on your screen.

If your computer does not have built-in magnification software, you can purchase brand names such as Jaws, Text Reader, ZoomText, Window Eyes, and Open Book. Information on how to contact dealers is included in our resource directory. If you own an Apple computer, a free magnifier called “Close View” can be downloaded from their disability site. Again, what works for one person may not work for another, so you might want to take advantage of free trial periods, which are offered by most companies.

If your vision is such that it is difficult to read even large print or magnified text, you might enjoy listening to audio books, which are available at no cost from a number of agencies and from the Library of Congress. These books cover a wide selection of subjects, and you will be provided with a special machine free-of-charge to play them on. Commercial audio books sold in stores can be played on any standard cassette tape deck.

Employment Issues

If you are losing vision, and you still need to remain in the work force, you should realize that you have the right to reasonable accommodations in order for you to function efficiently and effectively on the job.

You can expect your employer, for example, to provide adequate lighting in your work area. And, if you use a computer, magnification software and a text reader program are not unreasonable expectations. If you work for a company which has fifteen or more employees, or if you work for the state or local government, your rights are protected by law under the Americans with Disabilities Act.

Basically, the ADA states that if you are qualified to perform essential job functions except for limitations caused by your vision, the employer must consider whether you could perform those functions with reasonable accommodation. “Reasonable accommodation” might mean altering your work environment, modifying equipment, or even reassigning you to another position for which you are qualified.

For more information about your rights under the Americans with Disabilities Act, contact the Equal Employment Opportunity Commission. Our resources contain their current address, Internet location, and phone number. The information they provide is also available in standard and large print, on audio cassette, in Braille, and on computer disk.

Adaptability is a very important element of your T.A.S.K. force. By actively controlling your daily environment, you will be taking a large step
toward reducing the challenges of this disease to manageable levels; and the amount of help available to you is constantly growing. MD Support can help keep you up-to-date, so please stay in touch with us, either through our web site or through the updates we provide through the mail.

Support

Due to the growth of the Internet, in combination with public outreach organizations such as ours, millions of people around the world are sharing the knowledge and support they need to deal with central vision loss. Losing the gift of sight is never going to be easy, but it helps a great deal to know that we don’t have to try handling it alone.

MD Support hosts a large email discussion group and an Internet message board, bringing together hundreds of people daily to share their knowledge of, and experiences with, visual impairment. Internet email discussion groups, chat rooms, and message boards are an excellent way to communicate with others. They can be nearly as immediate as live conversation, and there is always someone who is ready to listen at any time of the day or night.

And, with special computer software, we don’t have to see to type or read. Recent technology allows us to send a typed message by speaking into a microphone. Our computers will then read aloud the messages which we receive. Speech software can be purchased on the Internet or at most computer supply stores.

There are, of course, other ways for us to communicate with people who share our condition. Vision centers, hospitals, and the Department of Veterans Affairs regularly have live support groups as part of their rehabilitation programs. Groups are also sponsored by many foundations, local charities, churches, and retirement centers.

No matter where you find it, a good support system is vital when living with vision loss. If you are experiencing vision loss, family members and friends are your most immediate source of support, especially if they are informed about your condition and your needs. Be open and communicative. You will usually find that others really want to help, but they often don’t know what to do. A good start would be to share this information with them.

Your best support will come from people who share your condition, or from people who are experienced in assisting the visually-impaired. That means finding or starting a group, either on the Internet or in your area, or locating a good rehabilitation counselor. You may feel intimidated by the prospect of joining a group, since it would mean interacting with new
people. You will, however, be surprised how easy it is when you have something in common which is as personal as vision loss.

Here is what one woman wrote about the help she received from our email discussion group:

“About three months ago I wrote to you for the first time. I had suddenly lost the sight in my left eye and felt desperate. My right eye’s vision was also disturbed, and it was more than I could handle. Many of you wrote back, including some wonderful doctors. You have restored not only my peace of mind, but my hope that I can do what needs to be done. You taught me how to react, where to go for help, and what to do and not to do. I would not have come this far without your caring and your help! I cannot thank you enough.“

Use the same tenacity that has gotten you this far, and try a support group, either on the Internet or in your town. Not only will you be helping yourself, but you will very likely find that you also have something valuable to offer.

Knowledge

The fourth and final element in your T.A.S.K. force is “Knowledge.” It is as powerful and effective as the others, but it is the easiest to acquire. Until the early 90’s, the average person could obtain information about macular disease only from a doctor or a medical library.

Since then, the Internet has cultivated the sharing of nearly everything written on the subject. Questions are answered, and answered immediately. That has dramatically reduced, and in some cases eliminated, the period of anxiety and depression that many people formerly experienced when they were first diagnosed.

Whatever the source of your information, whether a doctor, a support group, a rehabilitation specialist, a public service organization, the media, or a friend or family member, you will want to be sure that the facts are accurate.

- Confirm that your source is officially recognized by proper certification, licensing, or professional endorsement.
- Your source should be able to back up its statements with documentation.
- Don’t hesitate to ask questions or seek other opinions and viewpoints.
- If your source of information is making a profit, practice a bit of healthy skepticism before spending your money.
• If your source is a legal non-profit organization, you can check histories, organizational structures, and financial statements by contacting the appropriate governmental agency in your state.

Knowledge is power, but misinformation can be dangerous. Your safest bet is to learn as much as possible so that you can make educated judgements. Of course, you will always want to consult with a trusted professional about anything which might affect your personal condition or treatment.

Tenacity, adaptability, support, and knowledge: the four elements of your personal T.A.S.K. force. Strong defenses which, when combined, can help protect you against the emotional assault of vision loss.

It is a self-perpetuating cycle of success. Tenacity is the engine which can drive you to adapt your environment, strengthen your support system, and expand your knowledge. In turn, the confidence you gain will help to fuel your tenacity.

Living with central vision loss is not easy, but many of us who are traveling the same road know that it is much easier when you have help. The main thing to remember is that no one needs to be alone as they take on the T.A.S.K. of living with central vision loss.
What Can I Do to Keep Busy?

One of the most common concerns of the vision-impaired is how to keep busy. People who are used to filling their days with lots of activities often find it difficult to replace those hours with things that don't require good eyesight.

Here, in no particular order, are ways I have learned from our Internet community to remain vital and productive in spite of impaired vision.

• Purchase descriptive videos, which include narration to accompany the movies. For information, contact Descriptive Video Service in Boston at 800-333-1203.

• Listen to National Public Radio. Learn about it here.

• Listen to books and periodicals on tape. To find distributors, see the resources section of this site.

• While listening to those tapes, do something physical to stay in shape. Floor exercises, weight lifting, stretching, or yoga will improve your body while you entertain your mind.

• Enroll in low vision rehabilitation training for help in maximizing your capabilities. Medicare will usually pay for this. For information, contact your state's agency for the blind, which you can find in the resources section of this site.

• Join a live support group. To find one in your area, call your low vision specialist or contact one of your state agencies for the blind. If there isn't one near you, why not start one?

• Join an email support group or some other social media forum.

• Attend concerts, lectures, book readings, etc. Your church, parks department, or senior citizens group may offer group outings to events such as this.

• Start a garden.

• Take a class in water aerobics, meditation, or body conditioning.
• Become active in your church.

• Tape record your life history for your grandchildren.

• Take classes in Braille. It will open up a whole new world to you.

• For more information on this and other long-distance courses offered by the Hadley Institute for the Blind and Visually Impaired.

• Ride a tandem bike or go canoeing with your spouse or a friend.

• Learn to play a musical instrument by ear.

• Cook and bake. It may take longer than it used to, so be patient and enjoy the moment.

• Go for walks with other people or a pet.

• Do large-print word search puzzles and crosswords, either online or in print.

• Do jigsaw puzzles. Puzzles to play on your computer can be found on the Internet.

• Play bingo using large print cards.

• Purchase a CD that identifies bird songs. It's a perfect way to continue enjoying "bird watching."

• When traveling, play CDs of music relating to that area/country. Replay it later to remind yourself of the trip without having to view pictures.

• Like golf? You don't have to give it up if you have someone to play with. Most of the game is physical skill, not eyesight. Ask your playing partner to line you up with the ball (if you can't see it well enough) and then tell you about any potential hazards and the distance you need to cover. The rest is up to you. (And remember to buy your partner a drink at the clubhouse after the game, win or lose.)
• Most important of all, nurture friends and family members. Not only do they provide much-needed emotional support, but they are probably very willing to take turns driving you around to all of those things you are going to get involved in.

• This is only a partial list. If you would like to contribute your own ideas, please send them to me. I would love to hear from you!
What’s So Funny About Low Vision?

What’s so funny about low vision? Nothing really, but some humor can come from living with it. You know, those gaffes and missteps which may not be funny to anyone who hasn’t lived with visual impairment, but which can make us grin when we realize we’re not the only ones who commit them.

Lord Byron wrote, “Always laugh when you can. It’s cheap medicine.” And recent research has shown that it actually does make you healthier. This presentation, therefore, is dedicated to humor, featuring contributions from the people in our Internet community who understand visual impairment first hand. It won’t cure what ails us, but it might be one of the best treatments we’ll ever get.

I’d like to start with a short poem by Marion. She calls it “Macular Mayhem”.

I feel my life is all a blur:
I cannot tell a him from her.
I once approached a garbage pale
And thought it an attractive male.
And since I am a friendly soul,
I wave and smile at every pole.
And this is just the normal state
Of a macular degenerate.

Thanks, Marian. It’s good to know that I’m not the only one who talks to inanimate objects.

Faux pas like that abound in this strange world of ours. Like this one from Sharon, who wrote:

“We were listening to a guest speaker at church, and the topic was ‘Are you desperate enough for God?’ It was a powerful message and I was quite moved. “As we entered into the greeting area, I went up to a friend of mine and gave him a hug, then leaned in and whispered in his ear, ‘Are you desperate enough?’

“When I pulled back and realized that this was not my friend, but some elderly gentleman I had never met, I blushed and moved right along. I can only imagine how well this story got around at the senior men’s breakfast.

A somewhat similar story was contributed by Mary:
“My husband [she wrote] deliberately wore a bright yellow shirt when we went shopping. That made it easier for me to find him in a crowd. Well, I found a perfect purchase, but realized I didn’t bring enough cash. So I approached the yellow shirt and said, “I don’t have any money. Could I have your billfold?”

A strange voice said, “What?”

“Oh,” I said, “I’m sorry. I thought you were my husband.”

The African American gentleman looked at my fair skinned Irish mate and said, “No, I’m not your husband, but it looks like we have the same good taste in shirts”.

And speaking of shirts, Lorraine wrote about the time she was shopping for a blouse. She saw one on a mannequin and began fingerling the material. She let go quickly, however, when what she just THOUGHT was a mannequin pushed her hand away and said, “Ma’am, I’m not for sale.”

Shari’s faux pax was even more embarrassing. She wrote:

“George and I were invited out to dinner by his new boss and his boss’s wife. The restaurant was dark, but everything went well…until we prepared to leave. That’s when I reached for George’s hand so he could help guide me through the maze of chairs and tables. Only it wasn’t George. It was his boss. And it wasn’t his hand I grabbed. Oops.

“George explained my situation, but the wife didn’t seem to be as amused as her husband. She said to me, ‘You don’t LOOK blind.’”

To which I wanted to respond, “And you don’t SOUND like an IDIOT.” But I resisted, because George needed to keep his job.

And then there are those times when we simply don’t see things the way they really are. Like when Irving confused hemorrhoid cream for toothpaste and then worried all day that his teeth were going to shrink.

Or like when Jenny thought something terrible was happening to her recently-treated right eye. She keeps her reading glasses attached to a chain around her neck, and while preparing the evening meal, she put them on to see better.

Jenny began to panic when she noticed that her vision was much worse, and her eye was beginning to sting and water. She described it to her husband as calmly as possible, but real tears were also starting to flow. Her husband smiled and gently removed her glasses to show her a big thin slice of onion nestled in the bottom curve of the lens.
Vera wrote about the night she rolled over in bed to see what time it was. Her clock was always brightly lit, but that night she couldn’t see it at all. She panicked and woke her husband by yelling, “I can’t see!” He sat straight up in bed, then started to laugh.

Now she was screaming: “Didn’t you hear what I said? I can’t see!”
Calmly, he said, “Neither can I, sweetheart. The electricity is off.”

And another time, Vera wrote:
“I was taking my daily walk to the bank from my office. The big clock on the bank sign was always my point of reference as I got closer. But that day, when I got to where I could usually see it, I couldn’t! When I drew closer, I still couldn’t! My heart started racing. I was scared silly.
“When I got to the entrance, I saw that the clock wasn’t even there. It had been removed for repairs.”
Considering Vera’s luck with clocks, maybe she should just buy a talking watch.

We all have trouble locating our keys, finding our cell phones, and trying to change TV channels on our stomachs because we’re holding the remote backward. But I’ll bet every one of us can, the first time, every time, from three feet away, hit the snooze button on our alarms. Why is that?
Shirley keeps calling her son-in-law to come over and get rid of snakes in her yard. One of them turned out to be a long scarf that blew out of someone’s car window. Another snake was some black tubing left by the landscaper. She says she’s afraid no one will believe her now if a snake really DOES show up.

Pam decided to make a stir-fry. She threw pieces of chicken and other ingredients into a white bowl, mixed them together, and heated it all up for dinner. Turns out the bowl she used was half full of sugar, so dinner was provided by McDonald’s that night.

Dina thought she was going blind when the lens fell out of one side of her glasses.

James thought his vision in BOTH eyes had gone overnight until he realized his bedroom window had frosted over.

Carol thought her bag of almonds had gone bad until she realized she had popped a handful into her mouth along with her multivitamin capsules.
And then there’s Maxine. She reported that she came in all wet from watering the garden one evening. So she took off her clothes, and placed her wet socks and tennis shoes on the porch to dry overnight. Next morning, she opened the door to get her mail and found that what she thought were her socks was her brassiere. She said she wasn’t sure if her old mailman noticed. She said Ernie never actually mentioned it, but he seemed a lot friendlier after that.

It’s not so bad when we don’t recognize THINGS. But when we don’t recognize PEOPLE; that can be a social nightmare.

One Monday morning, while waiting my turn in the post office, I saw Sheila, a fellow teacher, at the counter. It has been over twenty-five years since my retirement, but that was Sheila, all right. I couldn’t quite make out her face, but she was talking a blue streak, as usual, to the postal clerk about something or other; and I would know that voice anywhere.

By way of greeting her, I very loudly joked, “You know, if some people weren’t so gabby, the rest of us might get faster service here!” To which I expected good old Sheila to bite back with something like, “And if you weren’t so crotchety, you could have gotten here BEFORE me!” Then everyone in line would have had a healthy laugh at our antics, and this particular Monday morning would have become a little brighter.

But she wasn’t Sheila. I don’t know who she was. She just gathered her purse, whispered, “I’m sorry, sir,” and slipped quietly away.

All I know is that my mumbled apology meant zip to her and everyone else in line, and I’ll never be able to show my face in the post office again.

So I decided to become a social hermit. Yep, if I couldn’t be trusted in public, I would just stay home and communicate by telephone. Then, at least, I would have an excuse to say, “To whom am I speaking?”

Speaking of telephones, a few years ago, I heard about a great service offered by our local company: free directory assistance for the visually impaired. This is a wonderful concept offered by most states, whereby a vision-impaired person can simply pick up his receiver, dial 1-411, and ask the operator to connect him at no cost.

So I called the phone company to sign up. After several attempts at hacking my way through a jungle of automated phone prompts and dead ends signified by some confused human whose final reply was “hmmm”, I came up with thirty easy steps to acquiring free directory assistance. I’ll list them for you to save you the time and trouble.
1. Make sure you're calling the right phone company. The company you THINK you belong to may have been bought out, merged, taken over, or split up anytime during the past billing period.

2. Call the billing department. Don’t call customer service, or you’ll be sorry. Also, don’t call 1-816-474-0516. That was obviously only one digit away from being the billing department of my phone company, and the person who answers will tell you so in no uncertain terms.

3. If you get this far, you’ll be connected, and you will listen to a 90-second commercial message. That is exactly how long you’ll remain on hold. It’s always 90 seconds. Never more, never less. Exactly the length of that commercial message. Curious.

4. When prompted by an automated voice, say your 10-digit telephone number.

5. When the voice prompts you to do so, say any number for which you hear the word “billing” in the recorded message. It was number four for me, but they later told me it might change at any time, so don’t count on it.

6. Say any number for which you hear the phrase “arrange billing payments” in the automatic voice prompt. I didn’t write down that number, because I knew I couldn’t count on it.

7. When prompted, say the last four digits of your account number from the upper left corner of your phone bill, which is neatly filed away somewhere upstairs.

8. Look for your hand-held lighted magnifier, and make your way upstairs. Locate the shoebox of last month’s receipts under the bed, find the one you are looking for (the one on the bottom of the pile), and make your way back downstairs to the phone.

9. Repeat steps 1-7, because you have been disconnected for taking too long.

10. Say the last four digits of your account number. The number will be in size 7 font, so you will need your magnifier.

11. Realizing you left your magnifier in the shoebox, climb the stairs again.

12. Find it, hurry back downstairs, and say the numbers.

13. Repeat the numbers several times slowly, because you are so out of breath that the automated voice keeps saying things like “I do not understand wheezing.

14. After several more tries, during which time you have become someone your mother would not even take to church, the voice says, “Please hold while I transfer you to a human who understands that kind of language.”
15. Check your pulse while listening to the entire second movement of a lovely string quartet by Mozart.

16. A human will eventually answer and ask you for your 10-digit telephone number.

17. Don’t bother to explain that you already did that back in step number four, because they don’t want to hear you whine.

18. Just give the human your phone number.

19. The human will ask for your name as it appears on your phone bill.

20. If you don’t know which page of the receipt that is on, don’t bother crawling upstairs again, because you mailed it with your payment.

21. Say any name, and hope the human doesn’t become miffed if you are wrong.

22. Miffed, the human will ask how it can help you anyway.

23. Say, “I would like to receive a request form for directory assistance exemption.”

24. If the human says “hmmm,” immediately ask to speak with a manager. That’s the secret. Don’t try to explain it to the human, because it will only get more confused and start transferring you to places unknown.

25. Listen to the third movement of that lovely string quartet. Then have a little lunch. Maybe take a course in Braille, which you’ve been meaning to do for a long time.

26. The manager will eventually come on the line.

27. Repeat, “I would like to receive a request form for directory assistance exemption.”

28. If the manager doesn’t say “hmmm,” you have succeeded!

29. You will receive the form in the mail in a few days.

30. Sign it, have your eye care specialist verify it, and mail it back to the address shown. That’s all there is to it.

And what do you do if the manager doesn’t know how to help you? Hmmmm . . .

So things like this happen a lot. We either don’t see it, can’t find it, run into it, or fall over it. And even when we think we have everything under control, we somehow still seem to find ways to draw unwelcome attention to ourselves.

Take Sharon for example. This is another Sharon, not the one who propositions elderly men in church. This lady bought one of those new voice recognition phones and was anxious to make her first call without operator assistance. Here’s what she wrote about her experience as she tried calling her house from the store.
“‘Home,’ I said into the microphone. Nothing happened. Then I realized maybe I wasn’t using the right tone. So I stood there just outside the entrance to the store repeating ‘Home’ in high, low, sweet and, eventually, not so sweet tones. Still nothing, but I wasn’t giving up.

“Before long, several people had gathered around with offers of transportation. Hey, maybe next time I won’t even turn the phone on. I’ll just yell ‘Home!’ and choose my ride.”

Hannah, one of our more progressive seniors, purchased that new phone that can carry on a conversation with you. It’s called Siri. She says the best part of Siri is that it will actually answer when you request to be beamed up by Scottie. Other than that, Hannah says she finds it to be pretty useless.

For example, she asked Siri to call Panera Bread in Charleston. It kept saying there was no listing for Panera. So she broke it down phonetically: “Pa-ne-ra”, to which Siri announced, “Sorry, we have no listings for dating services”.

Hannah said she and her husband were in the car at the time. It’s a good thing the windows were closed, she said, or he might have had to stop and help her look for Siri by the side of the road.

We CAN get pretty frustrated at times. But I think it’s forgivable, as long as we don’t let it get the best of us.

After her six-month eye exam, Olive’s ophthalmologist told her there was nothing he could do for her. “God did this to your eyes,” he said, “Now please leave, as I have other people waiting.” So Olive pinched his nose and told him God made her do that.

Eight-year-old Brittany got her first long white cane. It not only helps her navigate through the halls at school, but she says it also comes in really handy for “whopping” the boys who tease her. A little more training may be necessary for Brittany.

And then, funny things just seem to happen BECAUSE of us. And when they do, it’s usually best that we keep our sense of humor.

Patty sometimes has to close one eye to look at something close up. One day, her dentist numbed her for some work on a bad tooth. As he waited for the novocaine to take effect, he saw her closed eye and exclaimed, “Oh, no! I put your eye to sleep, too!” Patty thinks he seriously thought so, too, until she stopped laughing long enough to explain.
In my music teaching days, I took my children’s group to perform at a local choir festival. As usual, I brought along a portable light to help me see the score. As we entered the performance hall, the light dropped out of my folder and crashed to the floor, spilling its batteries across the carpet.

As my kids scurried around to pick them up, the harried festival monitor said, “Never mind those. We must remain on schedule.” To which one of my little sopranos scolded her with, “Mr. Roberts can’t SEE without his BATTERIES!” Not only did the monitor wait patiently, but my young wonders took first place at the festival.

If nothing else, having poor vision provides us with plenty of excuses for bumbling through life, whether it’s really due to our eyesight or not. To wrap things up, here are a few great excuses offered by our low vision community:

• When you go out with friends, you never have to be the designated driver.
• When getting engaged, you can encourage your fiancee to get you a diamond big enough to see.
• You can get seated on the front row of the airplane so you can “see the movie. (You know you really just want the extra leg space.)
• You can pass right by someone you don’t like and pretend you didn’t see them.
• You can get your spouse to cook the dinner because you can’t read the cooking instructions.
• You can be forgiven for introducing yourself to a tree.
• You never have to worry about cobwebs around the ceiling, dirty shoes, or dust on the top shelves. Out of sight, out of mind.
• You never have to be the map reader on trips, so you are blameless when your husband finds himself hopelessly lost.
• You can pretend not to notice that your children’s faces are covered in chocolate ice-cream so someone else will wash them.
• You still look the same in the mirror as you did ten years ago.
• You can’t read your calendar, so you have an excuse for forgetting birthdays and anniversaries.

You know, Mark Twain said that nothing can stand against the assault of laughter, and that includes vision loss. Which is why I hope our stories have made you chuckle.

Please remember to smile often. It not only helps you feel better, but it causes everyone around you to wonder what you’ve been up to.
A Blouse For Church  
(Edna’s Story)

All I wanted to do was press my blouse for church. So I found the board and my old steam iron with no difficulty (because I have learned to be very organized) and set them up in the kitchen. After plugging in the iron by feeling for the socket and somehow not electrocuting myself, I discovered that the reservoir was empty. As the iron heated up, I filled a measuring cup at the sink and returned to perform what used to be a simple procedure.

I never thought pouring water could be such a challenge. That was a tiny little hole, and I had to hit it directly with no central vision.

It would have been easy if I had a funnel, but who owns a funnel anymore? I guess I could have made one out of paper, but that would have meant finding paper, scissors, and tape. This shouldn’t be so difficult, and I don’t have the time!

I tried making a funnel out of my fingers and only made a mess. That’s when I decided to just wear the blouse wrinkled. Who would care, anyway? “I’m an old blind lady, for Pete’s sake,” I said aloud. “What do they expect?”

I started to cry. And that made me mad. And the madder I got, the harder I cried. Then a big tear dropped onto the blouse, and I flashed back to my mother sprinkling water on my pinafore with her fingers.

“How stupid of me!” I thought, and within an hour, I was at church with a freshly-ironed blouse done the old-fashioned way.
Getting My Mail
(Susan’s Story)

I was pacing slowly down the sidewalk, so I wouldn’t trip over that crack like I did the day before. With the mail in one hand, I shaded my eyes with the other. My sunglasses were the recommended kind, but I realized I should have worn my big hat to keep the sun from glaring off of them.

I heard the clack-clack of skateboard wheels coming at me head-on. A few years ago, I would have stepped aside, I didn’t know which way to step. So I just froze in place, hoping the pilot of that conveyance would have good maneuvering skills.

He didn’t. He collided with my left hip, and his ride escaped into the street. He ran after it, and I screamed at the sound of a blaring horn and tires scraping on loose gravel.

The boy returned unharmed and slammed his skateboard back onto the concrete walk. He stood in silence for a few seconds. Probably scowling at me. Then, with a push of a toe, he was off again, leaving me standing there wondering how I would get my mail from then on.
A Blurry Night Before Christmas

'Twas the night before Christmas, when all through the house
Not a creature was stirring, not even a mouse.
My stocking was hung by the chimney with care,
But I ripped it right down when I tripped on the chair.

Then out on the lawn I heard such a clatter,
I rose from the floor to see what was the matter.
Approaching the window, I stuck my head through the sash,
Since I'd closed it before, it made quite a crash.

The moon on the breast of the new-fallen snow
Glittered brightly on the shards of glass below
Then, what to my squinting eyes should appear,
But a blurry little sleigh, and eight limping reindeer.

With a little old driver and a temper so quick,
I hoped against hope that it wasn't Saint Nick.
But that's who it was, and he gave me the blame,
As he whistled and shouted and called me by name!

"Hasn't anyone told you your eyesight needs fixin'?
Look what you've done to Donder and Blitzen!
To the top of the porch! To the top of the wall!
Let's get out of here quick before this guy kills us all!"

So up to the house-top the coursers they flew,
With the sleigh full of toys, and Saint Nicholas, too.
As I dabbed at my head, and was turning around,
Down the chimney Saint Nicholas came with a bound.

He spoke not a word, but went straight to his work,
And filled my stocking, then turned with a jerk.
And covering one eye with a red-gloved hand,
Said, "Son, give yourself the gift of a vision exam!"

He sprang to his sleigh, to his team gave a whistle,
And away they all flew like the down of a thistle.
But I heard him exclaim, as he flew into the night . . .

"MERRY CHRISTMAS TO ALL, AND TO ALL SMARTER SIGHT!"
A Miracle

A miracle came my way when I awoke today.  
I saw my room in color, not just shades of gray.

My family in the photos smiled unblemished from the wall;  
The lamp that once was crooked now stood straight and tall;

The titles on my dusty books glowed clearly from the shelf;  
And, in the mirror beside my bed, I could see myself.

I reveled in that moment between wakefulness and sleep,  
But knew it was a fleeting gift I’m not allowed to keep.

So with some regret, I thanked the Sender of the prize,  
And let it go where all dreams go, as I opened up my eyes.
A Parable of Vision

God created light,
So Mankind could view the colors of Earth.
Then Satan created ultraviolet rays,
And Mankind covered his eyes.

And God created a bounty of fruits and vegetables,
For the better sight of Mankind.
Then Satan created tobacco,
And Mankind inhaled.

And God created intelligence,
So Mankind could build machines for seeing and learning.
Then Satan created ignorance,
And Mankind published manuals in small fonts and large words.

And God created language,
So Mankind could freely share knowledge.
Then Satan created greed,
And Mankind invented subscription fees.

And God created empathy,
So Mankind might help itself to heal.
Then Satan created insurance,
And Mankind invented HMOs.

And God spoke to Satan, saying,
“I have given to Mankind many wondrous things,
That he might see with the eyes of an eagle,
And you have thwarted me at every turn.
Don’t you have anything better to do?”

Then Satan sneered and created hopelessness,
And Mankind began to drown in self-pity.
So God raised Mankind high above the earth, saying,
“Behold all that I have given you.
Why do you let the shadows in your eyes
Dim the light in your mind?”

Then God grabbed Satan by the horns,
And flung him into the realm of the visually-impaired,
Who then awoke in great numbers and
Set about giving the devil Hell.

And Satan cried, “I thought you people were blind!”
“We may be,” they said, “but together, we see you very clearly.”
So the devil retreated in haste to his dark domain,
Where he ruled over the sighted who chose not to see.

And there he remained, befuddled, for the rest of his days.
I See

I see the sweet face of a child and her shyly penned words of love.  
I see stars that are bright in their patterns of gods in the gloaming above.

I see the one whom I married sleeping in the first dim light of dawn,  
And I find my way from the darkened room to put my slippers on.

I see the sepia photographs printing sun shadows on the wall,  
And every red leaf of the maple announces its fluttering fall.

I see every note on the page of a Beethoven bagatelle,  
And a smile from a sickroom sentinel assures that a friend is well.

I see strokes of a brush once held by the likes of Degas or Monét  
As they borrowed the colorful contours of a clear and crystalline day.

I see the well-rehearsed gestures of actors performing their scenes,  
Then follow them unhesitatingly into the darkness between.

I see this world in its wholeness, with clarity set apart  
From the inadequacies of troubled eyes. I see with memory and my heart.
The Promise

You called from across the river
Through the roar that filled the air.
“Show me where you crossed over,” you cried,
If you’re really there!”

We replied, “Yes, we’re here together,
And we’ll show the way to you.
But no bridge was there to help us.
Our way was not over the river, but through.”

“What if I start to sink?” you asked.
“We’re here to lift you up,” we swore,
“The struggle is one we’ll share with you,
Until you reach the shore.

There’ll come a time before too long
When you will stand on solid land.
Then you, too, will heed the cries
Of those who need your hand.

You’ll reach out, as did we,
And help someone else to live.
Your purpose will then be brought to light,
And the promise will be yours to give.