As discussed in “Macular Degeneration: The Inside Story,” 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.

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.

Since 1994, MD Support volunteers have been gathering every bit of information they can find about diseases of the macula. All of that information and a great number of resources can be accessed absolutely free-of-charge from our web site. We also publish the information in large print hard copies for those who don’t have access to a computer. In other words, we’re doing everything we can to help people deal with a situation that often leaves them feeling alone, depressed, and afraid.

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 “copability.” 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, Adaptability, Support, and Knowledge**
The T.A.S.K. force for living successfully with central vision loss.

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 include Gideon, who has begun a support organization in Israel.
Frances, who runs a support group in Nevada and who appears on television talk shows to discuss macular degeneration.

And Linda, who has developed her own web site, responding to email messages from anyone who writes for help.

These people have fought the urge to retreat by directing their energy toward public service. Others show 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.

These men and women 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 hyperinsomnia (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;
and finally,

• 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**

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.

Some of us may have decided to use mobility aids, such as a cane or a guide dog, even though we still have use of our peripheral vision. In such cases, the final two rules would apply:

9. Never take hold of a white cane; and
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 World Wide Web. 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.
Adapatability

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 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 blueblockers from a number of dealers listed in our resource directory. 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.

To help you further, MD Support can provide you with pocket-sized cards which contain information about macular degeneration and how to contact us. This is another good way to let people know about your condition if the need arises.

**More Helpful Hints**

- **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.
- **Get measuring cups that are individual.**
- **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

Many low vision devices are available, which can also help. Our resources include nearly two hundred dealers of products designed for visually-impaired people.
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.

You can also 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 a magnifying machine called a closed circuit television, or CCTV. With a CCTV, 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 CCTVs 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.

The MD Support web site contains a comprehensive listing of dealers in assistive devices, or you can receive the information through the mail by ordering from our publications list.

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.

MD Support provides contact information for more than seventy audio book sources, in addition to lists of state agencies for the visually-impaired, which can assist you further. Again, all of this information is freely available from our web site, or we will be happy to mail it to you in large print for only the cost of reproduction and postage.
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.
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 under brand names like Jaws, Window Eyes, OutSPOKEN, VocalEyes, and Text Reader. You can find names of all such products and their distributors in the MD Support resources.

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 support groups as part of their rehabilitation programs. Groups are also sponsored by many foundations, local charities, churches, and retirement centers. Your state government can help you locate groups in your area, and our resources include contact information for those agencies.
If you do not have computer access, and there is no support group near you, then you may want to start a group of your own. All it takes is a few interested people, a place to gather, and the kind of resource information which we can supply.

At this time, more than twenty-five macular degeneration organizations can be reached through web sites, by phone, or through the mail, and a large number of books have been published on the subject of low vision.

All of the macular degeneration organizations can be reached through our MD Portal, which is a page on our Internet site containing direct links to each of them, along with descriptions of their purposes, activities, organizational structures, and financial condition. The same information is in our resource directory, and future updates will keep you informed of new additions.

The MD Support bookstore is another excellent resource, containing all known titles on the subject of retinal disease. Each book is described and linked directly to its order page at Amazon.com, where it can be purchased with a credit card and received through the mail within a few days. If you do not have computer access, you can refer to the book section of our resources section to order the same titles through your local dealer.

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.
MD Support’s extensive resources include all of the current knowledge about diseases which lead to central vision loss. The information is free and easy to access, both on and off of the Internet, and it includes:

- A large, up-to-date library of articles and reports on the subjects of research, eye conditions, nutrition, and therapies.
- A complete glossary of medical terms specifically related to macular disease.
- Illustrations and descriptions of eye anatomy, specifically, the retina.
- Transcripts of informative discussion sessions with professionals in the field.
- An archive of accounts written by people who have undergone various treatments for macular problems.
- An archive of consumers’ opinions about low vision products.
- Eye tests to check and record your vision.
- A collection of illustrations and photographs showing how people see with various degrees of vision loss.
- Links to information about all conditions involving central vision.
- Links to recommended hospitals for vision care.
- Links to all other organizations which deal with macular disease.

This information is available for free on our web site, or we can send it to you in large print for only the cost of reproduction and shipping.

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 such as ours, you can check histories, organizational structures, and financial statements by going to the MD Portal on our web site or 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. And an important thing to remember is that you have MD Support on your side. All of our resources are at your disposal, and we are committed to helping you succeed for as long as you need us.

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. That’s what our outreach effort is all about, and I hope you will stay in touch with us, either by way of the Internet or through the mail.
Our Internet address and mailing address are at the end of this tutorial. An order form is also included for requesting our videos or printed materials. We hope our services will be of value, either to you or to someone you know. The main thing to remember is that, with the help of MD Support, no one needs to be alone as they take on the T.A.S.K. of living with central vision loss.

End

To receive free ordering information for the MD Support resources in large print, use the form on the next page. Remember, all of these documents may be accessed at no cost from the MD Support web site at www.mdsupport.org.

To purchase a fully-narrated video of this presentation, visit www.mdsupport.org/videos.html.

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