

UNDERSTANDING
Cone Dystrophy



University of Michigan
Kellogg Eye Center

Introduction

Many thanks to the patients and families affected with cone dystrophy who provided valuable insight for the content and layout of this booklet.

Thanks also to the Kellogg Eye Center Inherited Retinal Dystrophy Clinic staff, Low Vision Clinic staff, and Marketing Department staff for making this booklet possible. Our research into inherited eye disease is generously funded by the Foundation Fighting Blindness, the Elmer and Sylvia Sramek Charitable Foundation, and the National Eye Institute/National Institutes of Health.

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*Funded through a grant from the
FRIENDS of the University of Michigan Hospitals*

*Image on page 3 provided by the National Eye Institute,
National Institutes of Health*

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Learning about Cone Dystrophy

It can be overwhelming to receive a diagnosis of a condition that will affect your vision profoundly. Because vision affects so many daily activities, many people find it difficult to adjust to even mild vision loss. Armed with information, patients and their families can face the future confident that they know what to expect and ready to explore all the possibilities that life will offer.

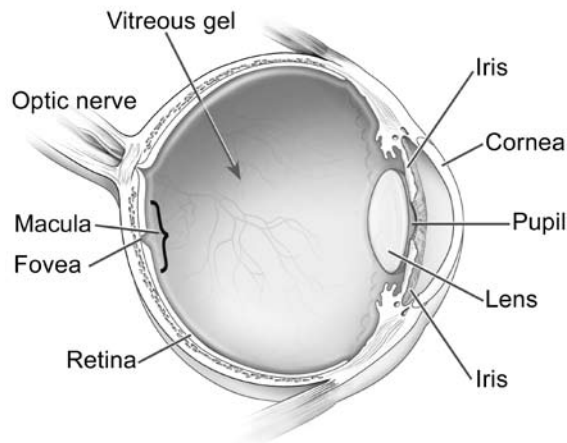
The purpose of this booklet is to provide that information to individuals with cone dystrophy and their families.

The first part of this booklet focuses on medical knowledge about cone dystrophy. Later sections deal with support and daily living.

Understanding Cone Dystrophy

Cone dystrophy affects about 1 in 30,000 people in the United States. The name refers to a group of eye conditions that affect the cone cells in the retina. The retina is the “seeing” portion of the eye, and consists of specialized nerve cells that line the back of the eye. There are two main cell types within the retina: rods and cones.

Cone cells are present throughout the retina. The center of the retina (the macula) has the greatest amount, and controls central (reading) vision and color vision. Rod cells are present throughout the retina, except for the very center (fovea). Rods help with night vision.



Cone dystrophy is a term used to describe a group of disorders that affect cone cells in the retina. This decreased function of cone cells can lead to decreased central vision, reduced color vision, and often sensitivity to bright lights. There are two types of cone dystrophy: progressive and stationary. In **progressive** cone dystrophy, symptoms become worse over time. In **stationary** cone dystrophy, the person has the condition from early childhood and symptoms generally stay the same over the person's lifetime.

Early-onset cone dystrophy is usually stationary, and is called achromatopsia. The term achromatopsia can be broken down into: "a" meaning without, "chromat" meaning color, and "opsia" meaning vision, or "without color vision." The term is a misnomer, because not everyone with achromatopsia is unable to see color, but it is still used to describe stationary cone dystrophy.

SIGNS AND SYMPTOMS OF CONE DYSTROPHY

Cone dystrophy mainly affects the cone cells. When the cone cells do not function, a person's vision relies more heavily on the rod cells. When the person is exposed to bright light, the rod cells and any working cone cells may become overwhelmed with light. This causes one of the main symptoms of cone dystrophy: "photophobia," or sensitivity to light. A "phobia" is usually considered

a “fear” of something, but “photophobia” refers to *sensitivity* to light, rather than an actual *fear* of light.

Children with cone dystrophy often have problems focusing on one image. Their eyes may “dance” or move back and forth. In many cases, the eyes may stabilize with time.

People with cone dystrophy typically have trouble with color vision, or in some cases of achromatopsia, do not see color at all. A person who does not see color may not even have a concept of what color is, as everything is seen in shades of gray.

Central vision and visual acuity in a person with cone dystrophy is typically decreased, while side vision is generally present. Both eyes are usually affected in a similar way. There is a large range in the age of onset for cone dystrophy, although most forms are diagnosed in childhood.

Understandably, individuals with a diagnosis of cone dystrophy want to know exactly what will happen to their vision. There is wide variation from person to person in the amount of vision loss and in how quickly the disease might progress. It is difficult for anyone to predict—including the doctors—exactly what vision will be like at a certain time in the future. Individuals with achromatopsia

typically have cone dysfunction from birth, and so the visual symptoms mentioned above are usually noticed early in childhood and are not expected to worsen over the person's lifetime. People with progressive cone dystrophy experience a worsening of cone function over time. Progression usually occurs gradually, over several years.

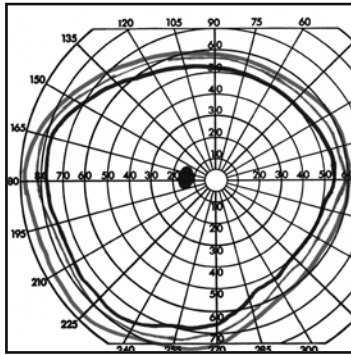
Although patients are concerned about going completely blind from the condition, this is actually uncommon for people with cone dystrophy. It is more likely that a patient may be considered "legally blind." This is defined as having best corrected vision equal to or worse than 20/200 in both eyes (which cannot be corrected with glasses). However, side vision usually remains intact.

For patients with cone dystrophy, the quality of vision often depends on lighting situations. In bright light, a person's vision might be blurry and washed out. However, the same person might feel quite comfortable in darker settings, such as at dusk, or inside with the curtains drawn.

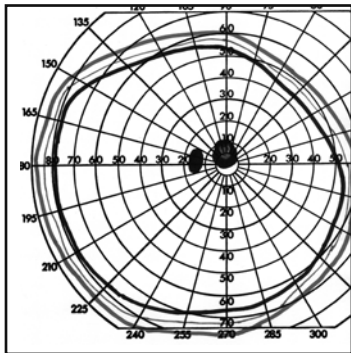
TESTING FOR CONE DYSTROPHY

You may wonder how cone dystrophy is diagnosed, and why so many tests are needed to diagnose it properly. In many cases there are no physical changes in the retina of someone with cone dystrophy. Sometimes the ophthalmologist must rely on subtle symptoms and findings to know which tests to order. It is not uncommon for a person to visit several doctors before arriving at the diagnosis of cone dystrophy. The following tests are normally done to arrive at a proper diagnosis:

- **Visual Acuity Testing** — Visual acuity is another term for visual clarity. Most people are familiar with this test, in which they read letters from a chart while seated at a certain distance. A person with normal visual acuity is said to have 20/20 vision. A person with 20/40 vision can see at a distance of 20 feet what a person with “normal” vision can see at 40 feet. This is expected to be decreased in a person with cone dystrophy.
- **Color Testing** — This measures a person’s ability to see color. A series of images composed of many small circles is presented to the patient. Someone with normal color vision can recognize numbers within the images. Other color vision tests may ask a patient to look at several small colored beads and place them in order. Individuals with cone dystrophy typically have trouble performing these tests.



Normal Visual Field



Cone Dystrophy Visual Field

■ **Visual Field Testing** — This test measures a person’s field of vision. A light is brought in from the side on a screen, and slowly moved to the center of vision. Patients press a button as soon as they see the light. For individuals with cone dystrophy, we do not expect the peripheral field of vision to be affected, although some may have a blind spot in the center of their vision. In the diagram at the bottom left, the black circle in the center represents the blind spot.

■ **Electroretinogram (ERG)** — This tests rod and cone function, and is important for confirming a diagnosis of cone dystrophy. In some cases, the ERG shows signs of cone dystrophy even before the patient is aware of symptoms or the doctor can see signs of cone dystrophy in the retina. This specialized test is performed in only a small number of centers nationwide.

For ERG testing, a numbing drop is put in the eye and a special type of recording contact lens is placed on the eye. Flashes of light are used to stimulate the retina. Electrodes measure the electrical response of the rods and cones to the flashing lights. This test is performed first in a dark room, then the lights are turned on and the eye is re-tested. The test is not painful, but some find it to be uncomfortable. The ERG of a patient with cone dystrophy shows that the cone cells are functioning abnormally.

- **Fundus photographs** — Using a special camera, your doctor can photograph the fundus, or back of the eye. The testing is relatively fast, but requires that the eyes be dilated. A person with cone dystrophy often has a normal-looking fundus, especially in the early stages of disease.
- **Fluorescein Angiogram** — This test may or may not be used at your visit. It involves a special dye (fluorescein) that allows your doctor to see changes that are not obvious in the normal exam. This includes changes in the deeper layers of the eye. The eyes are dilated and the dye is injected into a vein in the arm. A special camera records the dye as it passes through the blood vessels in the eye and highlights retinal structures. The resulting photos allow your doctor to identify retinal problems more easily.

TREATMENT FOR CONE DYSTROPHY

While there are no therapies today to cure cone dystrophy, there are two important options for helping individuals with the disease. The first is to make the most of existing vision by using tinted lenses, low vision magnifiers and aids. Second, some animal studies have shown that antioxidant vitamins can slow further vision loss. Research is ongoing. Some mice with cone dystrophy have been effectively treated with gene therapy, but it is unknown if the approach will work in humans.

Despite the lack of treatment for cone dystrophy, general eye checkups are still important. People with cone dystrophy are still at risk for other eye problems that may affect anyone in the general population. Some may be treatable with surgery or medications. Regular visits to a cone dystrophy specialist can also make you aware of current advances as we learn more about cone dystrophy and treatments that may help you.

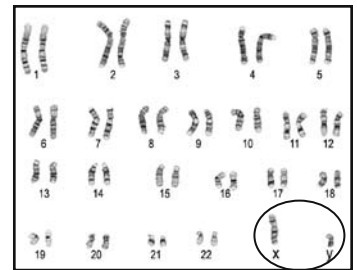
Genetics of Cone Dystrophy

Cone dystrophy is caused by changes in certain genes that code for proteins. These proteins are important to cone function. As changes may exist in several different genes, there are several different types of cone dystrophies. This also means different inheritance patterns exist among families with cone dystrophy.

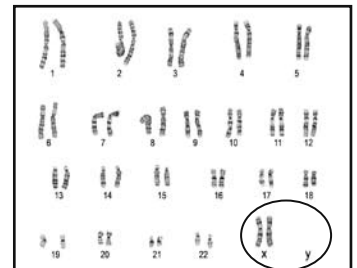
GENES AND CHROMOSOMES

Each cell in our body contains the same set of genetic instructions that tells our body how to function. Half of the information comes from our mother, the other half from our father. The information is found on structures called chromosomes. Each cell has 23 pairs of chromosomes, or 46 total. Every chromosome has many genes. A gene contains specific instructions for a particular function in the body, like eye color. Since we have two copies of each chromosome, we have two copies of most genes.

The only chromosomes that don't always come in pairs are the sex chromosomes—X and Y. Males have an X and a Y chromosome, while females have two X chromosomes. Thus, females have two copies of genes on the X chromosome, while males have one.



Male Chromosomes



Female Chromosomes

Sometimes, a gene may not function properly because of a “typo” in the instructions for one or both copies of that gene. This “typo” is also referred to as a gene change or gene mutation. When the gene doesn’t function as it typically should, it may lead to a genetic disease such as cone dystrophy.

Several genes can cause cone dystrophy when mutated. The type of cone dystrophy in a family and the way it is passed on depends on which gene has a mutation. The severity of vision loss may also depend on the location of a mutation within a cone dystrophy gene. Patients with questions about their personal form of cone dystrophy should be guided by experienced health professionals, such as an ophthalmologist or genetic counselor, who know about genetics and cone dystrophy.

INHERITANCE OF STATIONARY CONE DYSTROPHY — ACHROMATOPSIA

The majority of achromatopsias are inherited in an **autosomal recessive** manner. A small percentage of achromatopsia (called blue-cone monochromacy) is inherited in an X-linked recessive manner. See what follows for an explanation of these inheritance types.

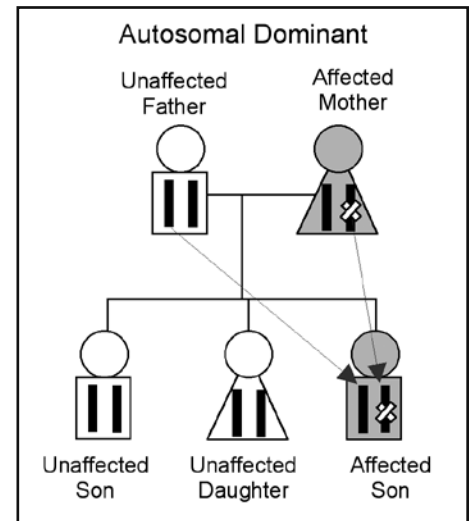
INHERITANCE OF PROGRESSIVE CONE DYSTROPHY

Progressive cone dystrophy is usually inherited in an **autosomal dominant** manner, but there have been cases of **autosomal recessive** and **X-linked recessive** described. We will therefore provide a brief overview of these types of inheritance.

The diagrams of family trees (pedigrees) below show different ways that cone dystrophy can run in families. A person with cone dystrophy is filled in gray. The black rectangles represent chromosomes. Gene mutations are shown as a white X.

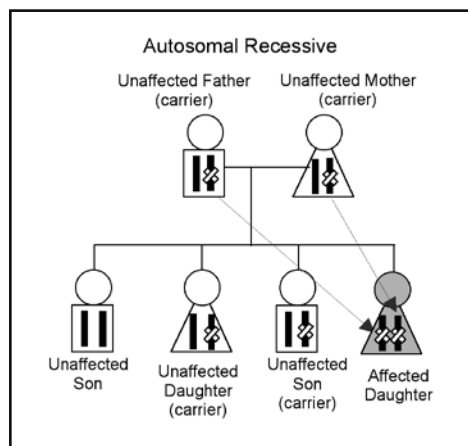
Autosomal dominant inheritance occurs when just one copy of a gene mutation causes cone dystrophy. The mutation causes cone dystrophy even when the second copy is normal. Some features of autosomal dominant inheritance are:

- The disease can be passed from one generation to the next: from parent to child to grandchild.
- Both males and females can be affected.
- When a person has a dominant form of cone dystrophy, he or she has a 50% chance with each pregnancy of having a child affected with cone dystrophy.



In some of the families with an autosomal dominant cone dystrophy, not every person in the family is affected in the same way. Some may be affected so mildly that they are not even aware they have signs of the disease. In rare cases, someone with a dominant genetic change may not show any signs of the condition, or may only show mild signs. However, he or she will still have a 50% chance of passing on the mutated gene.

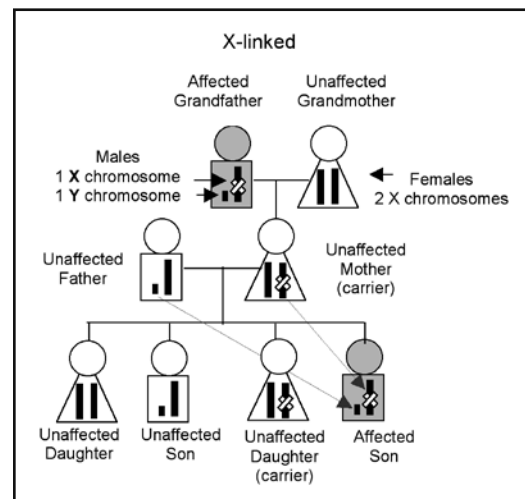
In **autosomal recessive** inheritance, on the other hand, a person develops the condition only when both copies of the gene don't work. That is, the gene from the mother and the gene from the father both have mutations. Some features of autosomal recessive inheritance are:



- Typically only one generation is affected.
- Both males and females can be affected.
- Individuals with one normal gene and one mutated gene generally don't show symptoms of cone dystrophy, and are called "carriers."
- When both parents are carriers, there is a 25% chance (with each pregnancy) the child will have cone dystrophy.
- It is possible for only one person in a family to have cone dystrophy if that person's form is autosomal recessive.

In **X-linked** cone dystrophy, the mutation is on the X chromosome. Males have an X and a Y chromosome and females have two X chromosomes. Because males have one X chromosome, if they inherit a cone dystrophy mutation on the X chromosome, they will have cone dystrophy. Females with one mutation and one regular copy of the gene typically do not show signs of cone dystrophy. If they do, the symptoms are usually mild and tend to occur later in life. Some features of the X-linked form of inheritance are:

- Multiple generations of males are affected, connected through unaffected females. For example, an affected grandfather would have a daughter who is a carrier. She may have a son who is affected.
- X-linked cone dystrophy is much more common in males than in females.
- When a male is affected, all of his daughters will be carriers and none of his sons will be affected.
- When a female is a carrier, each daughter has a 50% chance of being a carrier and each son has a 50% chance of being affected.



UNCERTAIN INHERITANCE

Often, a person diagnosed with cone dystrophy has no other family members with the condition. There are several possible reasons for only finding one person with cone dystrophy in the family:

- The cone dystrophy mutation was a new event in that person.
- Other family members have the same mutation, but have not been diagnosed with cone dystrophy. They may have a later age of onset, or have milder signs of the disease.
- The mutation has been in the family for a long time, but by chance, no other family members have been affected. For autosomal recessive cone dystrophy, carriers may have been present in the mother's and father's side of the family for several generations, but a child won't develop cone dystrophy unless both parents are carriers and both pass on a mutation to their child.

GENETIC TESTING FOR CONE DYSTROPHY

Testing a person's genes is an important part of diagnosing cone dystrophy. At the Kellogg Eye Center you may be asked to give blood for genetic testing. Samples are often sent to a research laboratory. Genetic information is obtained from a sample of blood, and cone dystrophy genes are examined to see if a mutation is present. Research laboratories do not charge a fee, but it will take months to get a result. The laboratory chosen depends on the type of cone dystrophy you have.

Research into Cone Dystrophy

GENE IDENTIFICATION RESEARCH

We currently know of six genes that cause cone dystrophy. Participating in cone dystrophy research may help researchers find new cone dystrophy-causing genes or develop a better understanding of these diseases. This information can be used to produce better treatments and ultimately a cure for cone dystrophy. Studies of many members of the same family may also be useful to identify cone dystrophy-causing genes. Sometimes, if we know the mutation causing your cone dystrophy, we can give you more information about disease progression or risks to family members.

RESEARCH FOR NEW THERAPIES

Scientists believe that researching the genetic causes of cone dystrophy will help in the development of future therapies. Research constantly produces new information, so it is difficult to report here on the “latest” findings. The best way to stay up to date is to ask your cone dystrophy specialist about current research and clinical trials at your next visit. You can also find reliable information online at:

- National Eye Institute www.nei.nih.gov
- U-M Kellogg Eye Center www.kellogg.umich.edu
- Foundation Fighting Blindness www.blindness.org

Help for People with Cone Dystrophy

It may be very hard to deal with a diagnosis of cone dystrophy. Many people have never heard of the disease and are unsure how cone dystrophy will affect them. You may or may not experience significant vision loss. If you do, you will not typically have to learn new skills overnight. People who have cone dystrophy lead successful and full lives. There are people to help you along the way. Below are recommendations for those desiring help with low vision adaptation, if and when they are needed.

LIFE WITH CONE DYSTROPHY

It is perfectly natural for someone with vision loss to feel anxious, fearful, angry, or unhappy. If your child has cone dystrophy, it is also natural to have feelings of uncertainty and anxiety over what the future may hold for him or her. It is critical that you discuss these feelings with your medical team. Support groups can also be very helpful.

People with cone dystrophy may be discouraged because there is currently no cure for the disease and very few treatment options. But if you or a family member is affected with cone dystrophy, there are many ways to take an active role to manage your condition.

This can help you live as independently as possible. The following pages offer suggestions and resources for living with cone dystrophy.

LIVING WITH CONE DYSTROPHY IN CHILDHOOD

If you are a parent of a child with cone dystrophy, it is important that you talk with your child about the condition. It is natural for parents to protect a child from knowing about the disease, but most often the child is aware of it and needs parental guidance. Children may be scared by having many medical appointments and may be unsure of what to expect in the future. Your child should be encouraged to talk with you if he or she has any changes in vision or needs additional help at home or school.

Parents struggle to find a balance between allowing the child to explore his or her surroundings, and stepping in to help when needed. Remember, your child is an individual who happens to have vision loss. Your child can have a normal childhood and grow up to be independent and successful, like any other child. As a parent, your attitude will dramatically impact your child's views of living with cone dystrophy and expectations for the future. It's important to maintain a sense of hope with your child, and never to give up. Open communication between parent and child will help.

While a positive attitude is crucial, it is also important to be realistic about the struggles for children and families dealing with low vision. Some parents find counseling for themselves, their child, or their entire family to be helpful. It can help the family maintain a sense of normalcy as they learn to adapt to the child's needs. It's also a good idea to introduce your child to several different peer groups besides the one at school. An extra set of peers in the community may help your child overcome difficulties with peers at school.

SUPPORT FROM SCHOOLS

Your child's teachers and school officials can be important members of your support team as you all work to help your child succeed. School districts or counties may assign a special education counselor. This person may follow your child until high school graduation. You should contact your child's teachers and principal before the school year begins to discuss arrangements your child may require. A yearly Individualized Education Plan (IEP) meeting is usually scheduled. This is a great way to stay in touch with school officials.

Children may try to hide struggles they experience, and can sometimes behave differently at home compared to school. Parents need to be alert for signs their child is struggling and needs help. Frequent contact with your child's teachers and counselors can make you aware of issues your child might not bring up at home.

Your child's teachers or school counselor may not know about cone dystrophy. A booklet like this one may be useful to help them understand your child's condition. They may also find information from your child's eye doctor helpful in understanding your child's condition and needs (e.g., limitations in visual acuity). Some children might benefit from different lighting or homework printed in larger text. Others may need extra time for tests, or assignments that do not require an ability to discern color. Some children may benefit from other low vision aids in school or from wearing special sunglasses or tinted lenses in school.

MAKING THE TRANSITION FROM HOME TO COLLEGE

Groups such as the Michigan Commission for the Blind can help you manage requests for services from the state after high school graduation. Other states have similar organizations.

Most colleges and universities have services for students with special needs like low vision. These include help registering for classes, obtaining books, making testing arrangements, finding a reader, transportation, etc. Many schools have programs that provide low vision students with equipment to record lectures. There may also be orientation workshops for students to familiarize themselves with campus before classes begin. Taking advantage of services requires planning ahead (as when ordering large-print textbooks), but there is no reason a person with low vision can't be successful at any university, or in any field of study.

Teenagers with low vision can become discouraged because of the social issues they face. They may feel different because they can't drive or enjoy certain typical teenage activities. Many young (and older!) adults forget how much they can do. While those with low vision do experience some limitations, most agree that their quality of life is largely dependent on attitude, not vision.

Many services are available to college students with visual impairment, but the student has to seek them out. Schools usually have an office for students with disabilities. As children enter the teenage and college years and become more independent, parents can help them learn to advocate for their own needs.

LIFE WITH CONE DYSTROPHY AS AN ADULT

Most adults describe living a full and interesting life despite the practical and social problems that can arise because of cone dystrophy. Although many individuals with cone dystrophy are diagnosed in childhood, some may not be diagnosed until they are adults. Others might not have a need for low vision adaptation until they are adults with established careers. When this happens, they may feel as though they can no longer perform their job functions. However, individuals with cone dystrophy can and do have a wide variety of jobs, from computer programmer to musician, and often find it unnecessary to change careers because of cone dystrophy. Some adults may need help in the workplace at first, perhaps through on-the-job training or a change in the worksite setting. In Michigan, the Commission for the Blind offers services to help adults with low vision adapt to work settings and to live independently.

In the later stages of disease, some people with cone dystrophy may need to apply for disability insurance benefits. This can be done by contacting your local state government social security office.

Many successful adults with low vision and the specialists who work with them stress the importance of focusing on what you can do, and maintaining a positive attitude. One woman with low vision has described

it this way: “If you were on the freeway and it was closed, you would find another way to get where you’re going. You wouldn’t just give up and stop moving.” All individuals, including those who happen to have low vision, have unique gifts and talents that make them valuable members of society.

AMERICANS WITH DISABILITIES ACT

The Americans with Disabilities Act gives civil rights protections to individuals with disabilities, such as low vision due to cone dystrophy. Its policies prevent employment discrimination and allow equal access to education, healthcare, and public transportation. If you have low vision, you should understand your rights under this act. For more information, you can call 800-514-0301 or visit www.ada.gov.

SENIOR SERVICES

Managing low vision after retirement is typically not different from managing the condition as a younger adult. Challenges can arise that would affect anyone at this stage of life. For example, people with cone dystrophy may still be at risk for other age-related eye conditions. It is important to continue regular checkups with your eye doctor and primary care physician. Individuals with cone dystrophy of any age may find support groups helpful.

Talking to Others about Cone Dystrophy

While it may seem difficult at first for you to understand your condition, it can be especially difficult to discuss your condition with others. Unlike other “disabilities,” a person with low vision often shows no outward features of the problem. Others may not be aware of your visual impairment. Many people feel awkward about discussing their visual needs. They don’t realize that others are probably eager to help in any way they can, but may not know how to approach you.

In deciding how and when to talk to other people about your condition, you and/or your child should find the right balance for you. Individuals with low vision should not feel pressured to educate everyone they encounter. Still, they can be advocates for themselves by sharing their needs with those who can help. Some find open and honest conversations to be most helpful. Others prefer to share written materials, then answer questions as needed. Several groups, such as the Foundation Fighting Blindness (blindness.org), can provide helpful information about your condition and can be accessed online.

Low Vision Clinics

WORKING WITH A LOW VISION SPECIALIST

Many individuals gain a great deal of confidence by working with a low vision specialist. These specialists can help you achieve independence, teaching you how to manage daily activities and make the most of your available vision. In addition, they can recommend assistive devices that will magnify or otherwise enhance your range of vision. Research shows that those who receive training from a low vision specialist are far more likely to use their devices properly and to benefit from them down the road. Low vision specialists can also put you in contact with rehabilitation services or other specialists.

LOW VISION EXAMINATIONS

To determine the extent of your useful vision you will need to have your eyes examined. Exams for low vision may differ from typical eye exams. During a low vision exam, your low vision provider may administer the following tests:

- Refraction — to assess your vision, determine whether glasses would be helpful, and provide the prescription for your glasses
- Visual field — to assess your peripheral vision
- Ocular motility — to assess how well your eyes move

Because low vision exams may involve many tests, they are often more time-consuming than standard exams. For instance, refraction may be done through a telescope or trial lens so you can judge which lens is best. Based on the results of the low vision exam, the low vision specialist will make suggestions for optical aids or techniques for adjusting to daily living activities. It may take several visits to learn how to use the device well. Some eye centers, such as the Kellogg Eye Center, have specialists who will travel to your home. They can help adapt your home setting to low vision needs.

LOW VISION AIDS

Some people may benefit from using special lighting to complete their daily tasks. Tinted lenses can provide the best light conditions for the eyes both when indoors and outdoors. These types of lenses may help patients achieve optimal vision. There are also devices and programs that make it easier to use computers. Some computer-based programs can act as magnifiers, or even convert text to audio formats. Patients with very late-stage disease are often helped by learning how to use a cane to find objects or curbs in their path when walking. They may also find a guide dog helpful. Some patients ask if it is necessary to learn Braille. Only a small number of patients in very late stages of cone dystrophy need Braille for reading.

LOCATING LOW VISION PROVIDERS

Most larger eye centers, including the Kellogg Eye Center, have low vision clinics. Your local ophthalmologist or cone dystrophy specialist should be able to give you a list of providers in your area.

LOW VISION SUPPORT GROUPS

Some people may be interested in meeting with others affected by vision loss. Meeting with others facing vision loss can provide useful support and let you know that you are not alone. Topics such as anger and fear about dealing with low vision are often discussed. There are more than 100 low vision support groups in Michigan. The Retina Clinic at the Kellogg Eye Center can give you a listing of these support groups. Another organization, the National Association for Parents of Children with Visual Impairments (or regional branches of this organization), can also offer support. Visit www.napvi.org.

Online chat rooms and message boards can also be helpful. Some organizations, such as the Foundation Fighting Blindness (www.blindness.org) have online message boards for individuals with cone dystrophy. However, if you have factual questions about your condition it is always best to talk to your ophthalmologist.

Vision Insurance

It is possible to obtain vision insurance to help with the costs of exams, glasses, and other assistive devices. Several government and volunteer organizations offer free or low-cost equipment to those with low vision. Check with your retina specialist for suggestions.

Resources

Below are a few organizations that can provide information about cone dystrophy and about living with low vision. These groups may also put you in contact with others in your area with cone dystrophy. The Retina Clinic at the Kellogg Eye Center has an extensive listing of resources for individuals with low vision. Please contact us if you would like more resources.

- U-M Kellogg Eye Center
www.kellogg.umich.edu
- Foundation Fighting Blindness
www.blindness.org
- National Eye Institute
www.nei.nih.gov
- American Foundation for the Blind
www.afb.org
- Foundation Fighting Blindness – Canada
www.ffb.ca
- Lighthouse International
www.lighthouse.org
- National Association for Parents of Children with Visual Impairments
www.napvi.org



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