



The Teacher's Guide to Helping a Student with Achromatopsia

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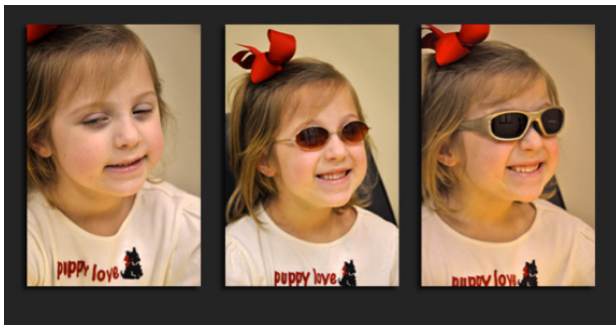
Achromatopsia is a rare genetic condition found in only one in every 33,000 to 50,000 births. Thus less than 10,000 Americans may have achromatopsia. Congenital achromatopsia is a condition in which all or most of the cone cells fail to develop or function properly. Cone cells normally provide clear central vision, color vision and our ability to see in bright lighting. Patients with achromatopsia have primarily rod cells to see with and these rod cells are functional only at low lighting levels.

Day Blindness (Hemeralopia)

Life with Achromatopsia is a battle against the glare. It is a glare so powerful that it can overwhelm the patient in all but the lowest light levels. The picture to the right demonstrates the vision of an achromat without special filters.

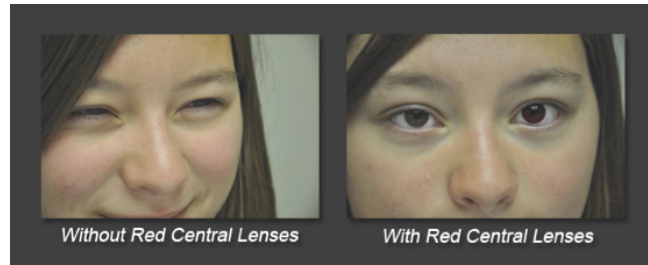


These children are literally blinded by the light. This severe day blindness is called hemeralopia. This is the most significant problem a person with Achromatopsia experiences. This severe intolerance to light can severely impair the child's vision. Rather than improve vision, as it does for most of us, light profoundly obscures their vision. If we control the light, we greatly improve the functional vision of achromatopsia patients. Achromats usually see much better at night and in low light situations. They may only enjoy going out in the evening.



A child too young to wear contacts lenses may wear very dark lenses in the eyewear for inside plus additional sunglasses for outside. Dark red lenses may be required.

From about age 8 or older a student may be fit with special contact lenses that contain special tints to greatly lessen the Hermeralopia. Note the difference in the squinting without and with the red filtered contact lenses.



Lighting Adaptations for the Classroom:

- The student must be allowed to wear the dark filtered eyewear inside and hats when needed.
- The student must be allowed to sit in an area that lessens direct exposure to bright light.
- Students with filtered contact lenses may only require the contact lenses inside.
- In some cases, adjustments in room lighting may be required.
- Determine if the achromat is comfortable for outside recess. Hats and sunglasses will be necessary when outside.
- Using a dark color paper or cloth on the desk will reduce glare from overhead lights.
- The child should not sit near any projectors which may have a bright light.
- The child must sit with windows behind them. Shades for the windows may be required in some cases.
- Whiteboards have a tendency to reflect large amounts of glare for a child with Achromatopsia. Reducing the lighting by the whiteboard may help the student see the board better. Also due to these issues, they should be allowed to go to the whiteboard, chalkboard or SmartBoard to see the information clearly.

Profound Colorblindness

The second problem is a lack of color vision in children with Achromatopsia. Achromatopsia can be divided into Rod Monochromatism and Blue Cone Monochromatism. In Rod Monochromatism, this is often a total loss of color



vision, but some children may have incomplete forms and may see traces of some colors. In Blue Cone Monochromats, only visual input from the rod cells and blue cones still function. Thus these patients retain the blue channel of color vision. They lack the red and green channels. This does not mean that they see the color blue as most do, but that objects that are blue may be more easily seen.

Which crayon is red? Which is blue? This is what the achromat faces daily in the classroom.

Classroom Adaptations for Colorblindness:

- The child should not be constantly challenged as to whether he or she sees a color, but rather provide support by labeling crayons or colored pencils.
- Attention should not be drawn to his or her color vision loss.
- Educational materials that use color-coding will not work with achromats.
- Limit or modify tasks that require color-coding such as a fill pattern of lines by pen rather than using colors.
- Colored markers can be labeled to let the child do simple color-coding tasks. Color-coded map projects are usually very difficult. Work out how these will be handled. The student could do a pattern to fill in versus a color or use labeled markers.
- Using colored chalk or markers may not be helpful and may not be able to be differentiated by the child with Achromatopsia.

Reduced Visual Acuity

The third problem is reduced visual acuity related to the loss of cone cells, which normally reside in the center of the retina providing our sharpest vision. The vision of the child with Achromatopsia is also constantly affected by the amount of light present. In our examination room with the lights lowered, the patient may read the acuity chart better, but be severely hampered when the lights are turned up. If we control the lighting, the child's visual acuity, though still impaired will be functionally improved.

The vision of an achromat will vary up and down based on light exposure. Seeing the child function well in one setting with less light does not mean the child can see to function in bright light. And, conversely seeing the child function very poorly in bright light does not mean the child cannot see much better in lower light or with the proper filtered eyewear or contact lenses. Most achromats have vision in a range of 20/80 to 20/200. However bright light can temporarily, but dramatically wash out the vision.

Classroom Adaptations for Reduced Visual Acuity:

- If lighting controlled with filtered eyewear, contact lenses, or room lighting modification, children with Achromatopsia will be able to function quite much better in a regular classroom.
- Children with vision loss including Achromatopsia will hold all of their work much closer than normal. They may lean over their reading material or bring it up closer. This provides more magnification of the material they are reading and should be allowed.
- Achromats should be allowed to sit closer to the chalkboard or whiteboard.
- These children may use high powered eyewear to help their eyesight with dark filters or high powered reading glasses.
- The use of low vision devices with small magnifiers and video magnifiers may be needed to help lessen the eyestrain these children have.
- Large print worksheets, tests and quizzes should be provided for the child. These should be good quality and high contrast to help the student see them better.
- Large print text books should be evaluated on a case by case basis by their VI Teacher. Many students will reject them due to their size. In junior high and high school, many times it is better to have large print text books at home for students to use in the evening when they are fatigued and have normal sized texts at school. All standardized educational tests should be done in large print.
- Some students with Achromatopsia can function adequately with normal print if they have adequate filtered eyewear or contact lenses. But, they will need to read at a closer distance.

- Additional time may be needed for all tests and quizzes given in the classroom. It will take the student longer to read and study the problem. All standardized testing should be done with extra time.
- In junior high and high school math courses as well as high school sciences, it should be noted that small subscripts may be difficult for the student to see even in large print at times. Therefore, extra time in testing is needed.
- Achromats may be hesitant to continually ask what is on the board. The teacher should monitor the student's ability to see the board and consider providing handouts of notes.

Nystagmus

Nystagmus is an involuntary rhythmic shaking or movement of the eyes back and forth. This is often one of the first things that may alert parents that their child may have a vision problem. Nystagmus adds variability to their vision. The faster the movement of the eyes the worse the student's vision will be. Stress is just one of many factors that may affect the speed of the nystagmus and thus the clarity of their vision.

Classroom Adaptations for Improving Nystagmus:

- Avoid fatigue and stress in schoolwork as these can increase nystagmus and thus reduce the visual acuity temporarily. Teachers may reducing the volume of work if the child fatigues easily.
- Allow for rest periods and reduce work if the child fatigues severely.
- Avoid the stress of timed tests or make special time allowances to lessen blurred vision from increased nystagmus.

Emotional and Social Impact

The mechanics of dealing with all of these problems can create a whole set of social problems. The day blindness may cause constant squinting, looking down to avoid light and wearing dark sun lenses inside. All of these impact a child's interaction with other individuals. It can be especially difficult for a young person. The need to wear dark red eyeglasses inside can impact their appearance and lead to



taunting by other children.

Taunting and bullying are common because of the difference in appearance and vision. The appearance can be dramatically improved when filtered contact lenses can replace the dark red glasses.

Strategies to Help with the Emotional and Social Impact of Achromatopsia:

- Create open communication between yourself and the student. Make sure they feel comfortable coming to you if they are not able to see something or having trouble with other students.
- Educate the entire class about the child's vision including the need to wear dark glasses and hats, constant squinting and color vision issues.
- Watch for teasing and taunting by other children and take action to prevent it from continuing.

Visual Fields

The visual field is the combined central and side vision of a child. Visual fields are usually only affected in the very center of the visual fields for a child with Achromatopsia. Their side vision is usually normal if light is well controlled.

However, in bright lighting without adequate filters, achromats must squint their eyes to overcome the light and glare which results in a temporary functional reduction of the visual field. This can be dangerous in outside physical activities.



Visual fields and the student's mobility can be improved with sunfilters and hats with visors. It is important to allow achromats to wear dark filters inside and filters and hats outside. When filtered contact lenses are worn, the inside filtered eyewear is usually not required. Without filters, the child may appear very impaired in mobility.

Progression and Prognosis

Achromatopsia is a very stable condition. It is very rare for vision to decrease over time. Thus Orientation and Mobility Training, long cane training, and/or Braille are not usually required for these students. Training the student in these areas with the concept of “in case vision decreases” may waste time that the student can be using to further their academics in the traditional classroom.

Special Services

All Achromatopsia students will need an Individual Education Plan (IEP). These students should be listed in the school system as a child with a visual impairment to allow them to receive additional services throughout their education. The IEP should be developed before the child begins school and then should be reevaluated at least yearly. In the IEP, the services of a VI teacher as well as the use of low vision devices, glare and lighting issues, large print and other low vision techniques may be specified for your child. Extensive Orientation and Mobility services are not usually required but an O & M evaluation should be considered if safety concerns arise. Proper filtered eyewear or contact lenses will usually solve the mobility problems seen in patients squinting without adequate filters. Filtered contacts are usually much more effective than filters in eyewear.

Special Services for Your Child:

- Ask your child’s teachers and VI teacher to visit www.achromatopsia.info to learn more about achromatopsia.
- The teachers or VI teacher may email the Low Vision Centers of Indiana with their questions. To discuss a specific child, a release from the parents is required.

Low Vision Care

Eyewear

Most achromats have significant refractive prescriptions and should wear prescription eyewear or contact lenses. Dark filters must be placed in the eyewear or contact lenses. Dark red is often the most effective since it allows only low energy red to reach the retina. This allows the rod cells to function, which would bleach-out in normal bright light. As soon as a child is old enough, custom filtered contact lenses can be prescribed. This requires a low vision specialist trained in working with achromatopsia. Age 8 to 11 is a common time to consider filtered contact lenses.

Low Vision Aids

The most important low vision aids are the filters used to control the light. Bifocals or reading eyewear can benefit many achromats and may lessen visual fatigue. A small hand held monocular telescope can enable the student to see the board. Even a small digital zoom camera can be a helpful aid for the board.

Physical Education Issues

The eyes of a child with achromatopsia are not fragile. But the combination of reduced visual acuity and overwhelming glare may further impair vision and place the child at risk of injury in many physical education activities. Each child's abilities are different. We should look at each situation to determine, what your child can do safely without eliminating all physical education. Some sports like rugby or football may be possible while tennis, racquetball or baseball may be dangerous as the child may not see a fast moving ball approaching.

Adaptations for Physical Education:

- The PE teacher, the classroom teacher and teacher's aid should understand the student's problems, particularly the issues of aversion to the light, reduced visual acuity and lack of color vision.
- The student must be allowed to avoid bright outside sports.
- The student must be allowed to wear sunglasses and hats inside and/or outside as needed in any sports activity.
- The student must have the option to substitute safe comfortable activities for those activities that he or she cannot do safely.
- The student must avoid fast moving ball sports like baseball, softball or tennis. These are often dangerous since the child may not see the approaching ball.
- If the student is to participate in any type of contact or ball sport, the participation should be cleared with his or her eye doctor.
- Adequate sport protective eyewear should be worn.
- The student's IEP (Individualized Educational Plan) should contain a statement of the limitations on physical education.

More Information on Achromatopsia

For more information on Achromatopsia, visit www.Achromatopsia.info . This website has many articles and videos to help understand what a student with Achromatopsia sees and how their eyesight is affected by this condition.