

# Explaining Albinism Vision



Eye problems in albinism result from the abnormal development of the eye because of a lack of pigment and often include:

- **Nystagmus:** Regular horizontal back and forth movement of the eyes
- **Strabismus:** Muscle imbalance of the eyes, “crossed eyes” (esotropia), “lazy eye” or an eye that deviates out (exotropia)
- **Photophobia:** Sensitivity to bright light and glare
- **Refractive Error:** People with albinism may be either far-sighted or near-sighted and usually have astigmatism
- **Foveal hypoplasia:** The retina, the surface inside the eye that receives light, does not develop normally before birth and in infancy
- **Optic nerve misrouting:** The nerve signals from the retina to the brain do not follow the usual nerve routes.

Vision issues of albinism are life-long, as the lack of or reduced melanin in the eye, results in permanent changes to the retina and the optic nerve routing. This can result in lack of clarity in vision, lack of binocular vision, photophobia and nystagmus with inability to function on moving objects quickly and lack of depth perception. For some with albinism, prescription glasses can improve clarity or help dampen nystagmus, while sunglasses (prescription or not) are essential for most to wear outdoors year round, or in bright light inside, to both protect the eyes and to significantly improve vision.

Various optical aids are helpful to people with albinism, and the choice of an optical aid depends on how a person uses his or her eyes in jobs, hobbies or other usual activities. Some are prescribed bifocals that have a strong reading lens, prescription reading glasses or contact lenses. For reading and close work they may use small magnifiers, desk or portable magnifiers, tablets and computers with accessible features or apps. When out travelling they commonly use monoculars or binoculars, while many with lower vision require navigation aids that are commonly found in smart phones and tablets or use bioptics for vision viewing.

## Measured vision versus functional vision

Measurements taken in the optometrist or ophthalmologist rooms measure what the eye can see in stable, stationary conditions. The measurement in the better eye (often corrected, with use of glasses) is used in determining eligibility for things like driving licences, support at school, disability pensions and government transport or taxi scheme funding. While this gives a base level to understand the vision, those with albinism are not all the same and vary greatly in how the vision operates, not only between individuals, but also for the one individual with varying personal or environmental conditions.

In Australia if a person with albinism has a measurement of 6/18, this means that they will have to be 6 metres away to see something that a sighted person can see from 18 metres. A measurement above 6/60 usually places a person in the legally blind category, while 6/18 is usually the minimum vision for education support and gaining a driving licence.

Functional vision is what we see in varying conditions, how things influence how well we see in our daily lives (not in perfect, stable, clinical conditions). It is particularly important in schools and work places, where the day is structured, to consider how we can accommodate functional vision for different times and conditions. When applying for NDIS or Work Place Modifications (Job Access), the measurement is not

as critical, because it is about what you need to achieve your goals or work tasks using your functional vision, although the measurement is used as a base level to understand visual acuity.

## **Variations in functional vision**

Variations in the structure of the eye, or how much pigment is produced in the retina and iris, will influence how well you see and can explain some of the functional vision differences between individuals who have the same clinical measurement. Those with greater misrouting of the optic nerves will often have greater problems with depth perception, while those with strabismus may have more issues with binocular vision – and both may be exacerbated in poor lighting (too dark or too bright).

## **Effects of Sunlight**

The retina does not absorb light due to the lack of (or reduced) pigment, reflecting light within the eye, generally causing difficulties with glare in those with albinism. Bright sunlight, glare from clouds, surfaces like snow, sand or water, glare from windows or lighting inside, not only causes a “white out” (as when you look directly into the sun) and temporary blindness, but also severe pain. Long-term exposure to the sun without sunglasses, with UV rays entering the eye, can cause permanent damage. It is therefore important to make sure sunglasses are rated as blocking both UVA and UVB rays, even on cloudy days. In perfect lighting indoors, those with photophobia may see well, however glare from whiteboards, tables, white paper and different forms or positioning of lighting, will again reduce functional vision.

## **Nystagmus**

Nystagmus will also affect functional vision to varying degrees, depending on the movement – some have greater range or speed of movement than others. This will also vary within the one individual, usually being more exaggerated or faster when they are ill, physically tired, stressed, have eye strain after reading for a time or simply because it is the end of a long day trying to focus. The eyes tire more easily with nystagmus and it takes longer to focus on an object as the eyes search for the perfect position, making it difficult to focus when they are moving, or on a moving object. Having short breaks during an activity requiring concentrated vision, or changing activities regularly can help prevent eye fatigue and strain.

## **Supporting functional vision**

Less than perfect conditions can affect all those with albinism, but small adjustments can help to improve vision. Outdoors wearing hats and sunglasses, seeking deep shade, having darkest tint on car windows, keeping your back to the sun and trying to avoid being outside between 10am and 2pm (11 and 3 DST) can all improve functional vision. When indoors, knowing which type of lighting suits you (yellow or white lights, fluorescent or not), wearing a peaked cap or having blinds and matt surfaces to reduce glare, sitting with your back to windows while also ensuring it is not too dark, will improve functional vision. Adaptive technology (both mechanical and electronic) will significantly support and improve vision for a range of activities at close or near distance, and to move safely around the community.