

Preschoolers will benefit from **regular check ups** from a paediatric ophthalmologist, monitoring the progress of vision development (normally delayed in those with albinism). Any strabismus (turned eye) can be monitored and any treatment fully discussed. Any “patching” of one eye or possible surgery to reduce strabismus or dampen nystagmus, is generally more successful if performed before 8 years of age. Prescription glasses cannot correct the major vision issues with albinism (incorrect routing of the optic nerve and changes in the retina), but some children benefit from prescription glasses to dampen nystagmus or slightly improve clarity.

At all ages, regular visits to an optometrist (and occasionally an ophthalmologist) can check for changes in the eye **not** related to albinism. Many children develop a refractive error such as near or long sightedness and have glasses prescribed, but for the child with albinism it is even more important that this is picked up quickly. To have an additional condition that further reduces vision, is an unnecessary challenge that can usually be catered for.

As there is reduced or no melanin in the eye of those with albinism, it is important to **protect your child’s eyes from the sun and reflected glare** (both UVA and UVB rays), even on cloudy days. This not only causes pain, but can damage the eyes over time. A good quality pair of sunglasses (UPF rated 50+) that fit closely or wrap around are an essential item for everyday wear. For those who wear prescription lenses, you can get “fit over” sunglasses (worn over prescription glasses) or sunglass frames that clip onto the normal glasses frame. The lens colour for sunglasses is a personal choice – the child will generally be able to tell you which one allows them to see better.

The **wearing of hats and sunglasses** can be an issue with babies and toddlers as they may initially pull them off. It pays to quietly persist, having the same expectations for siblings and role modelling this yourself. They will eventually work out that they are much more comfortable when the glare is reduced. Glasses with a built in strap, or flexible glasses that are less likely to break, can be purchased for babies. As they get older, the wearing of sunglasses or sports safety glasses and a hat will protect the eye, reduce pain and improve functional vision in bright environments, enabling them to participate with peers in activities.

Tinted car or house windows can also reduce glare, along with blinds at home when sun is low on windows. Some of those with photophobia have had success with funding for these through NDIS.

Sports/activity protection glasses that can have prescription lenses fitted are an excellent idea for active teens with albinism. They not only improve vision and reduce glare, but also protect the eye from balls or other players that may not easily be seen. Swimming goggles with extra dark tints in a range of lens colours or mirror surface, help reduce glare in swimming pools – once again let the child choose the colour that

works best to improve vision, as it will vary from child to child. Safety sunglasses are also available for older children undertaking gardening or craft/hobby activities that require eye protection. A hat or cap with a wide brim further reduces sun light or glare, even in winter, and can also be of benefit inside where lighting is an issue for the child.

Eye fatigue will be another issue for most of those with low vision, that may result in headaches and reduced functional vision, especially at the end of the day. The eyes are constantly searching for the best position to see things, especially in those with nystagmus, working harder than peers with full vision. Fatigue can be reduced by ensuring the child has the best accommodations in order to see and to change the activity before fatigue sets in, giving the time for eyes to recover. Making sure that your child is wearing any prescribed glasses, using magnification suitable for the activity, correct lighting and variety of activities, will reduce fatigue. Alternating between close, middle and distance vision can be a great help and as they get older use the 20/20/20 rule. It has not been officially researched, but many with albinism recommend this rule to avoid fatigue when reading or using close vision for extended periods – every 20 minutes, look 20 metres away for 20 seconds.

Accommodations that may assist in preventing fatigue – everyone is different:

- Lighting from behind or over the shoulder when doing close work or activity
- Use a magnifier to suit the activity
- The work or screen is at the best distance to see (while maintaining good posture)
- Text is clear, without serifs and letters not too close (egCalibri font)
- Diagrams or pictures are simple (not too much small detail)
- Screen brightness is adjusted to suit (your child will know what is best)
- Background of screen or paper used
- Reverse the text (eg white on black)
- Limit the time on any one close activity (10 minutes for a young child)
- Have regular rest breaks, interspersed with physical activity.
- Avoid prolonged screen time for recreation.
- Try to do close work earlier in the day when eyes are fresh.
- Use listening stories at bedtime when eyes will be tired.

Working with a low vision provider will give you ideas to help your child with albinism (of any age) to use their vision more efficiently and reduce eye strain and fatigue. An orthoptist will be able to undertake an annual assessment of the child's functional vision (now required for NDIS plans), while an assistive technology specialist (AT) will recommend suitable technology for your child, based on their age and level of vision. If they are at school and have a specialist visiting teacher, you will be able to discuss suitable technology for your child at the student support group meetings.