

## SENSORY AND PHYSICAL NEEDS: OCULOCUTANEOUS ALBINISM

Oculocutaneous albinism is a genetic condition which affects **vision and sight**. It also impacts upon sensitivity to sunlight.

### The main facts:

- People with albinism are born with little or no pigment in their eyes, skin and hair
- It is not associated with cognition – most children with this condition are able to learn in line with their peers
- 1 in 17000 people are born with some type of albinism in the UK
- It is generally congenital – inherited
- Is a spectrum condition, ranging from mild to severe and chronic
- Can occur on its own or with other conditions, such as aniridia (missing or incomplete iris) and cataracts (clouding of the eyes)
- Difficulties in vision are not usually corrected through glasses or contact lenses
- There are two types:
  - Oculocutaneous Albinism – affecting eyes, hair and skin
  - Ocular Albinism – primarily affecting the eyes

### The main difficulties associated with oculocutaneous albinism

Nystagmus	<ul style="list-style-type: none"> <li>• The involuntary rhythmic movements of the eyes, usually from side to side, but can be up and down or in a circular motion</li> <li>• Impacts reading speed and accuracy</li> <li>• Impacts ability to interpret information, particularly in graphical form – use photos where possible</li> <li>• Allow a lot longer to read, or encourage the use of text-to-speak software with headphones</li> </ul>
Reduced near vision	<ul style="list-style-type: none"> <li>• Impacting ability to interpret information on a worksheet, in a book,</li> <li>• Will finding learning to read difficult</li> <li>• May benefit from learning braille</li> <li>• May benefit from enlarged scripts</li> <li>• Double space handouts and worksheets</li> <li>• Will become visually fatigued more easily</li> <li>• As the student will require a predominantly auditory environment, ensure that auditory distractions are kept to a minimum, so the student can focus upon learning and the teacher</li> <li>• Struggles with walking up kerb, and slight bumps in the pavement</li> <li>• Reduce glare from shiny surfaces</li> <li>• Keep notes brief and to the point</li> </ul>

	<ul style="list-style-type: none"> <li>• Be aware of visual stress and do not expect to read for long periods</li> </ul>
Reduced distance vision	<ul style="list-style-type: none"> <li>• Will struggle to focus on the board</li> <li>• Seat at the front of the class</li> <li>• Use an I-pad linked to the board, if possible</li> <li>• Provide a laptop and electronic form of the information for student to be able to write on using a tablet</li> <li>• Will struggle to see traffic coming when crossing the road – ensure they are guided</li> <li>• Provide white or yellow lines on steps</li> </ul>
Reduced or Increased periphery vision	<ul style="list-style-type: none"> <li>• May be distracted by movement which occurs in the periphery vision</li> <li>• May jump when approached as the student doesn't see you coming towards them</li> <li>• Use auditory processes – warn that you are approaching them</li> <li>• Student may tilt their head at an unnatural position</li> </ul>
Photophobia	<ul style="list-style-type: none"> <li>• Extreme sensitivity to sunlight</li> <li>• Ensure they wear a hat outdoors</li> <li>• Provide shade when outside</li> <li>• Do not expect to be outside in sunlight for long periods</li> </ul>
Fatigue	<ul style="list-style-type: none"> <li>• As increased concentration and effort is required to perform everyday tasks, the student will tire more easily</li> <li>• Provide opportunities to rest the eyes, by listening to music</li> <li>• Quality of work may deteriorate throughout the day</li> <li>• May require time and space to rest during the day – a sensory room would be ideal for this</li> </ul>

### Access arrangements in examinations:

The condition is complex and can range from mild to severe. A specialist teacher for VI must be involved (usually provided by the Local Authority for where the student lives) who will assess the degree of disability.

It is important that any access arrangements reflect the student's normal way of working, and are based upon what they need; they will vary from student-to-student.

### The most common arrangements needed within exams are:

- Extra time -up to 100% depending upon the nature and degree of disability. However, this must be balanced against the fatigue experienced by having to concentrate for prolonged periods of time
- Reader – for students with severe visual impairment
- Modified papers – either Braille or enlarged scripts
- Practical assistant during practical exams
- Rest break for those severely impacted with fatigue
- Late/early opening – for students who become tired throughout the day and require a time of day when they are able to focus and concentrate

### For further information visit:

The following websites might help in understanding and supporting the condition.

- It is the responsibility of the Local Authority to provide specialist support in the form of a trained teacher for Visual Impairment.
- All provision within your locality is outlined within the Local Offer of your Local Authority.
- Contact your local authority SEND department for more advice.

❖ [www.allaboutvision.com](http://www.allaboutvision.com)

❖ [www.nhs.uk](http://www.nhs.uk)

❖ [www.mib.org.uk](http://www.mib.org.uk) (Royal National Institute for the Blind)