



Factsheet 10

Visual behaviours, implications and possible support strategies for working with children and young people with CHARGE.

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Isabelle Russell-Eggitt's article in this pack – 'Clinical assessment of vision for children with CHARGE' – highlights the following visual conditions associated with CHARGE: visual acuity loss, dazzle, visual field loss, delayed visual maturation, retinal detachment, corneal health and coloboma.

Coloboma

There are a number of different types of coloboma and the type of coloboma directly influences the choice and effectiveness of the support strategies used – as well as the resulting visual behaviours.

The severity of a coloboma can range from mild to severe. An iris coloboma, for example, is relatively mild and anophthalmia is at the most severe end of the spectrum.

If only a small part of the iris is missing, then the child's vision may be normal. Nevertheless, they may experience difficulties adjusting to bright light, because the pupil may be unable to shrink/alter in size sufficiently in response to changes in lighting levels. This links to the visual condition which Isabelle Russell-Eggitt refers to as "dazzle".

Interventions

To help individuals cope with fluctuating light levels indoors it may help to move them in relation to the light source. Blinds can also be used to control the amount of light in the room and reduce glare and brightness. Outside it can help if individuals wear



a cap, tinted glasses or a visor to cut out glare from the sun. These may also be useful indoors.

It may also be beneficial to allow more time for the individual to adjust to the different levels of lighting when moving from bright lights to dark or vice versa. This extra time for visual accommodation can allow the individual opportunities to maximise their independent mobility skills. Instead of relying on an adult for guidance they can develop self-help strategies, and learn to wait and allow for visual accommodation before continuing on their journey.



Retinal colobomas in CHARGE syndrome can have a more severe and noticeable effect on vision, notably visual field loss.

Visual field loss

If the lower part of the retina is affected by the coloboma, this results in an upper visual field loss, where the upper section of a visual image may be difficult or impossible to see (Brown, 2010).

This has direct implications for viewing anything above face level – for example tall peoples' faces, TVs, boards in classrooms. Crucially, any sign language presented in the affected visual field may be visually inaccessible to individuals with CHARGE.

If the coloboma is on the upper part of the retina, the lower visual field is likely to be affected. The individual may have difficulty with mobility, changes in levels, negotiating paths, steps etc.

The nature and extent of visual field loss should be determined so that appropriate support strategies can be put in place. For example, an upper visual field loss may require the individual to be appropriately positioned in class so that the most natural head position and posture can be adopted. This is likely to be more sustainable and effective over time.

Brown (2013) further highlights the effects of a visual field loss and a disrupted vestibular (balance) sense in individuals with CHARGE. The combination of these two elements may require further consideration and significant adjustments to the positioning and posture of the individual to allow sustained optimum visual access.

Isabelle Russell-Eggitt also notes that the vision in both eyes is rarely affected to the same degree in people with CHARGE. This may affect an individual's depth perception, and ability to judge speed and distance. Mobility may be affected for some children, particularly in unfamiliar environments.

Having said that, many individuals with different vision in each eye adapt without realising it and sometimes require little or no extra provision. However, if the vestibular sense is also disrupted, it may cause additional problems and the child may need extra support.

General acuity

CHARGE will affect how well an individual sees and any impairment can vary from a slight reduction of visual acuity (some minor blurring of images etc) to no light perception or vision at all. It is important to get an accurate visual acuity measurement, ideally

clinically, to ensure that support materials are provided in the most appropriate format.

Clear photographs, print and symbol size, colour and contrast should be considered in any printed materials. Busy pictures and pages should be reduced. Overlapping print and picture should be avoided. Consider instead which information is essential to the lesson or activity. The reader's visual acuity may also affect the choice and use of technical aids such as magnifiers, CCTVs, laptops etc.

Delayed visual maturation

People with CHARGE and additional needs may also have varying degrees of delayed visual maturation. Visual stimulation exercises in different environments, using a variety of resources, may encourage development of vision and help children improve some of their basic visual skills.

Retinal detachment

A heightened risk of retinal detachment is associated with retinal coloboma. Responsible adults should be mindful of the risk of retinal detachment and take extra care when supporting someone during contact sports or core activities which carry risk of a bump to the head.

If someone suffers a significant knock to the head their vision should be checked as soon as possible.

Corneal health

People with CHARGE may have a reduced ability to blink and close their eyelids fully. Their eyes can then become dry, red and painful – which can cause visual acuity to be further diminished. Regular clinical checks should be carried out to ensure that optimal eye health is maintained.

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Brown, D. (2010) Vision Issues for People with CHARGE Syndrome. *reSources*. 15(1).

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