Supporting families when poor vision is confirmed – Part 2

Please read this Good Practice Point in conjunction with Part 1 - Identifying children with visual disorders

This guide was developed to assist health visitors to appreciate their vital role in supporting families of infants and children who have a visual disorder. It provides the foundational knowledge needed to understand the conditions affecting children with visual impairment, their needs, and the services around them.

Children with visual impairment often have multiple vulnerabilities. The majority of these children:

- Have visual problems from birth, or from infancy
- Have poor vision due to brain disorders (cerebral visual impairment) rather than due to isolated eye disorders
- Have other disorders or impairments[1]

Also, children living in socioeconomic deprivation and those from minority ethnic backgrounds are more likely to have impaired vision when compared to other groups[1].

Please see our other Good Practice Point on Identifying children with visual disorders - Part 1.

Common terminology used

1. Visual impairment (VI)

VI is categorised using the level of visual acuity in the better seeing eye or with both eyes open:

- Moderate visual impairment*: vision of 0.5 logMAR or worse (approximately halfway down a standard vision chart)
- Severe visual impairment / blindness*: vision of worse than 1.0 logMAR (unable to see the top letter on a standard chart)[1].

(*using international accepted definitions)

Children with very restricted field of vision when both eyes are open are considered to have visual impairment.

Children with poor vision in only one eye are not considered to have visual impairment if the other eye has normal vision. These children may still need additional support despite 'only' having one affected eye.

2. Sight Impairment

In the UK, the Certification of Vision Impairment certifies individuals as Sight Impaired, or Severely Sight Impaired.

3. Amblyopia

For all childhood eye diseases, amblyopia (abnormal development of cerebral visual pathways due to limited stimulation during visual development) is an important factor. The brain develops good vision during a time window in early childhood. This development is dependent on good quality visual stimulation during this time window (which effectively close at age 8 years). Poor vision due to amblyopia may be permanent if treatable eye conditions which limit visual stimulation are not treated during the sensitive time window of development: the 'sensitive period'.

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4. Refractive error

Refractive (focusing) problems are a treatable cause of poor vision:

- Hyperopia, or long-sightedness, where focusing correction is needed to see objects in the near range
- Myopia, or short-sightedness, where focusing correction is needed to see objects in the distance
- Astigmatism, in which eyes focus light differently in different directions and correction is needed at both distance and near
- Anisometropia: where the focusing power is significantly different between two eyes, increasing the chance of unilateral amblyopia

Early detection of significant refractive error allows for early use of glasses to support visual development. Myopia rates are increasing globally[2], however, fortunately, permanent, untreatable visual impairment due to refractive error is uncommon in the UK[1].

5. Strabismus

Strabismus is the term given to squint, or the condition where the eyes are misaligned (e.g., one eye pointing in or out when the other eye is looking straight ahead).

Causes of poor vision

Blinding conditions can affect the visual pathways in the brain and all parts of the eye. Approximately 1 in a 1,000 children are affected by visual impairment or blindness each year[1].

Key causes of reduced vision in children in the UK are[1,3]:

- Cerebral visual impairment: the commonest 'cause' of childhood visual impairment, where there is an acquired or congenital disorder involving the visual pathways in the brain.
- Optic nerve disorders: either due to a congenital (such as optic nerve hypoplasia, which may be associated with hormonal and other brain defects) or acquired defects (for example due to tumours, or to raised intracranial pressure).
- Retinal disorders: these disorders include retinopathy of prematurity, with children affected by other complications from their preterm birth, and genetic conditions such as inherited retinal dystrophy, which may have impacted on other members of the family.
- Cataract: opacity of the naturally clear lens inside the eye. In recognition of the importance of early intervention for this treatable disorder, every neonate is tested for this as part of the newborn and infant physical examination programme: the red reflex test is used. A light is shone into an infant's eye, with the examiner looking for any obstructions in the reflection from the back of the child's eyes.
- Congenital anomalies of the whole eye or globe (such as microphthalmia, small eye, and anophthalmia, severely small and under-developed eye, or coloboma, in which the eye has not developed fully, and a part of the retina is missing) where both eyes are affected, also lead to VI.

Members of the eye and visual neurodisability team

Hospital and community-based children's eye services within the UK are multidisciplinary[4]:

- **Ophthalmologist:** medical doctors and surgeons who manage diseases of the eye and help to diagnose children with the cause of their sight loss, intervene with medical and surgical treatment where appropriate, and help to ensure that further sight loss is avoidable where possible.
- **Optometrist:** trained in managing refractive error and supporting eye health, who can help to optimise visual function with glasses. However, the majority of severely visually impaired children and young people will need additional help, so optometrists support function through provision of appropriate low visual aids.
- **Orthoptist:** trained in assessing and managing visual development disorders, including amblyopia and eye movement disorders. They can give detailed reports on visual functions to help with monitoring or with understanding the child's capacities.

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- **Eye clinic liaison officer, ECLO:** provides emotional and practical support to families affected by sight loss, working closely with eye clinic staff, educational teams, and the sensory teams in social services.
- **Qualified Teacher for the Visually Impaired, QTVI:** Teachers specialising in teaching children and young people with a visual impairment. They work closely with the ECLO and child's other teachers to ensure appropriate developmental and educational approaches. The referral process for QTVI support differs in different areas, but teams typically accept referrals from health and educational professionals, and in some areas they will accept referrals directly from families.

Treatments

For children with poor vision, optimisation of any visual function they do have, and habilitation, or optimal use of all their capabilities for education, socialisation and their tasks for daily living, is crucial.

Low vision aids (such as magnifier and targeted lighting) and adaptive technology (such as audio assistance and tablet-based assistance) are used to ensure that they are assisted in reaching their full potential.

Refractive correction may be useful – glasses can provide some meaningful improvement, even in cases where vision is very poor due to irreversible causes.

Children with unilateral amblyopia (that is, with one good seeing eye, and therefore children who cannot be classified as visually impaired) can have occlusion therapy: patching of the good eye to strengthen the development of visual pathways from the poorer seeing amblyopic eye.

Good practice points for health visitors

- Be aware that the child with visual impairment is likely to also have other impairments and disorders.
- Community paediatrician support and liaison with others can be vital for ensuring that the child is known to local developmental support units.
- Specialised educational support is key and starts in infancy, as pre-school children learn through play and sensory experience: there should be input from QTVI from the earliest stages of development.
- Children with visual impairment and blindness benefit from regular eye reviews to ensure that visual function and eye health are optimised.
- A complex list of eye disorders are responsible for childhood blindness in the UK: parents and families often need a lot of support to understand their child's disorder. This understanding is key to the parent being an advocate for their child's health and navigating the different health professionals involved in care.

Getting Support

Sources of support include the QTVI and ECLO teams.

The following charities may also be helpful:

- Guide Dogs https://bit.ly/3u4AcLa
- Royal Society for Blind Children (RSBC) https://bit.ly/3HspBgi
- Royal National Institute for the Blind (RNIB) https://bit.ly/3Hu6F0A

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