

Visual Impairment in Batten Disease

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BATTEN DISEASE FAMILY ASSOCIATION

Together we WILL make a difference

The importance of vision

- ▶ Vision loss sometimes viewed as ‘the least of their problems’ when the child has severe and complex needs
- ▶ Around 80% of learning is through vision
- ▶ Vision acts as a bridge between information from our other senses
- ▶ Vision unifies, co-ordinates and is informed by input from touch and hearing
- ▶ The gradual loss of vision in Batten disease has a catastrophic impact on learning, independence and quality of life

Support for visual loss

- ▶ Vision will eventually be lost, even light perception
- ▶ There may be a small area of useful vision for a long time
- ▶ Visual processing difficulties are common, even when vision appears to be unaffected
- ▶ Addressing vision loss is critical in supporting the child's functioning at school and at home
- ▶ Specialist support from a qualified teacher of the visually impaired is essential
- ▶ Every learning and social interaction opportunity must be adapted to enable the child with visual impairment to engage and enjoy alongside their peers

Visual Impairment

- ▶ Visual impairment usually happens after the onset of seizures/physical difficulties in the infantile and late infantile forms of the disease
- ▶ Vision loss is often the first symptom of the juvenile form of the disease
- ▶ Signs of vision loss may be very subtle and difficult to spot for both parents and professionals
- ▶ Loss of central vision first
- ▶ Loss of colour vision
- ▶ Difficulties focusing on objects/pictures/faces
- ▶ Eye hand coordination increasingly affected
- ▶ Eventual loss of all vision including light perception
- ▶ Maximising current vision and preparing for further loss
- ▶ Support from qualified teacher of the visually impaired is essential
- ▶ Multisensory impairment advice and support can be accessed from SENSE

Maximising current vision and preparing for further loss

- ▶ The qualified teacher of the visually impaired will assess and regularly monitor the child/young person's vision
- ▶ Advice on adapting all learning resources and strategies will enable school staff to enable full participation in learning and social interaction
- ▶ Children and young people can be taught 'adaptive skills' to prepare them for the loss of vision
- ▶ The use of Moon, Braille or objects of reference can ensure continued participation in learning activities
- ▶ Audiobooks, tactile books and individually adapted learning resources can all be used to support learning
- ▶ The visual memories built up when the child had vision can be used very effectively to support learning
- ▶ Support from the Orientation and Mobility specialist is vital in maintaining independence skills for as long as possible

Practical strategies

- ▶ There are lots of sources for multisensory toys, resources and ideas
- ▶ The VI specialist teacher, SENSE and the local authority multisensory specialist teacher can suggest suitable toys and equipment as well as sharing multisensory strategies and resources such as sensory massage
- ▶ Sensory stories, talking and tactile books, visually stimulating toys can all maximise any remaining vision and help the child use their other senses more effectively
- ▶ Activities that encourage focusing and tracking are helpful in maintaining visual skills
- ▶ There are many IPAD and computer programs for children and young people with little or no vision

Practical strategies

- ▶ Music activities can be combined with real objects and 'sensory effects' to help with understanding and participation
- ▶ Makaton, on-body signing and music cues support the child's involvement in classroom routines and circle time
- ▶ Videos of memorable events such as trips out, family activities or favourite activities in school can be enjoyed time and time again, helping to recall events in long term memory and stimulating communication
- ▶ A predictable classroom layout with play and learning materials in the same place and accessible to the child in a wheelchair or supportive chair supports independence for as long as possible
- ▶ There will be an opportunity later in the day to share ideas and good practice!

EHCPs and visual impairment

- ▶ There is an entitlement for children and young people to have their needs arising from severe visual impairment and the necessary provision identified in the EHCP
- ▶ A VI or MSI teacher should be assessing and monitoring vision and providing support and advice-this is a condition in which vision is inevitably lost
- ▶ This input should be specified and quantified in the EHCP
- ▶ The changing needs of the child/young person over time should be recognised
- ▶ The need for direct teaching of adaptive skills such as braille or moon, independence skills and the equipment needed should all be specified

Supporting parents and carers

- ▶ Parents and carers may feel very guilty that they have not 'noticed' the deterioration in vision-the child/young person adapts gradually to the loss and finds 'different' ways of doing things
- ▶ Sharing ideas and strategies helps to ensure consistency as well as involving and empowering parents and carers
- ▶ Information sharing is really important between the hospital, school and home
- ▶ Information on current visual functioning in school is really important when the child goes to the Eye Clinic-the usual eye tests can be difficult and emphasises the deterioration-the child's visual functioning at home or school is much more important!

Support for vision loss is essential for every child or young person with Batten Disease!

Thank you!

