Visual impairment, specific medical needs and medication

The best of both: working together to support children with visual impairment and additional complex needs

A series of leaflets exploring ways that the QTVI (Qualified Teacher of Visually Impaired children) and other professionals can achieve an effective working relationship together and ensure the best outcome for children with special requirements.

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A child with a combination of disabilities is likely to receive continued support from several agencies, each to address a medical, educational, therapeutic or social need. Each supporting professional may have their own expertise, priorities, methods of working and aims for the child.

In this series of leaflets we look at the above scenario and explore ways that the QTVI can support effective team work with other professionals. We aim to discover how good communication and joint working can help to:

- eliminate seemingly conflicting or confusing practice for both professionals and parents
- avoid, or solve, practical problems
- co-ordinate working practice, aims and targets to ensure the best possible outcome for the child.

Other titles in the series include:

- Visual impairment and physiotherapy
- Visual impairment and occupational therapy
- Visual impairment and speech and language therapy
- Visual impairment and orthoptics.

How medical practitioners and the QTVI can achieve the “best of both”

This leaflet explores the role of medical practitioners (primarily focusing on the role of the nurse) and the QTVI in their joint working with children who have MDVI (multiple disabilities including visual impairment).

Who addresses the medical issues?

Medical professionals supporting a child with MDVI may include paediatrician, specialists for vision, hearing, orthopaedics, epilepsy, etc; community or school nurse; and health visitor.

A QTVI is most likely to come into contact with medical practitioners when supporting children in a special school, or when a young child is supported through a Team Around the Child (TAC) approach. Early Support is a recognised way of providing co-ordinated family-focused working. It brings together everyone who supports the child and family (www.education.gov.uk/childrenandyoungpeople/sen/earlysupport).
How does TAC work?

Where possible, the family chooses a keyworker, who could be a medical or educational professional, then they meet regularly with the team to discuss their child’s progress. Each professional provides an update and the team agrees integrated goals, eg both visual and physical targets could be addressed if the QTVI works with a child during their session in the standing frame. TAC helps families to address a wider range of issues arising from their child’s complex disabilities. These might include accessing benefits, procedures for housing applications or adaptations, accessing short breaks/respite care or support for siblings, managing the statementing process and transition into school.

TAC provides opportunities to discuss both medical and educational issues. Observations are shared. The meetings help to raise awareness regarding the child’s needs and strengths in different areas and contexts. Supporting professionals can then adopt a more holistic approach when working with the child.

Working together

When a child is referred, the QTVI will ask the parent’s permission to share information with certain other professionals involved.

Information from the QTVI about the child’s visual and developmental progress can be a great help at the clinic, especially when children don’t co-operate or perform as well as they can with the medical practitioner. Some parents come away from appointments feeling frustrated because their child has cried or slept throughout the consultation. Other parents may find it difficult to identify areas of concern, especially if they have limited experience of typical child development.

Visit records from vision, hearing and developmental clinics can help the QTVI to understand the child’s visual and other issues. This can be a great help when working with the child.

The children

In the first issue of this series we discussed the changing population of visually impaired children. Improved prevention, early diagnosis, and effective treatment has resulted in fewer cases of sight loss amongst typically developing children, but an increase in the number of children with a vision impairment and additional complex needs. Improved neo-natal care means that more children survive premature and difficult births (1). Ongoing medical care in hospitals, homes and schools prolongs the lives of those with severe and life-limiting disabilities.

Within the school population, there is a relatively high incidence of vision impairment in special schools. The risk of profound or total sight loss increases with the severity and complexity of other disabilities (2). There is evidence, in particular, of a high prevalence of visual impairment in children with learning disabilities, especially children with severe or profound and multiple learning disabilities (3). It is not unusual to find several children in a PMLD class (profound, multiple learning disabilities) having support from a QTVI.
The reason for this is that a large proportion of the brain’s capacity is concerned with visual processing, including links between vision and other processes, eg motor control or language. Damage to the visual cortex (most commonly from lack of oxygen at the time of birth) can range from specific visual perception issues to total sight loss. Damage to other areas of the brain might indirectly affect other visual skills such as hand-eye co-ordination or recognising faces.

Other disabilities can also impact on visual development, visual learning and visually directed tasks. Healthy development of our functional vision relies on being able to attach meaning to the things we see. A baby notices a toy or piece of food, and is motivated to explore it further. He will feel, taste and smell, shake, bang and squash it. Next time he sees the same object he will remember and recognise it. When a disability impedes this process, these connections may not be made.

Children with complex needs frequently have ongoing health issues that require a high level of support from medical professionals. Some of the most common health issues are epilepsy; feeding/digestive problems; and cerebral palsy. Vision impairment features in certain other medical conditions, diseases and syndromes. These include septo-optic dysplasia, CHARGE syndrome, and genetically transferred progressive diseases like Sanfillipo and Batten’s.

**Epilepsy**

Damage to or atypical development of the brain can result in a high risk of developing epilepsy. Seizures are common in children with complex disabilities, and can sometimes be difficult to control. Epilepsy can take many different forms, from brief absences to prolonged tonic-clonic seizures. Some seizures may cause unusual facial or body movements, or behavioural changes. Children with epilepsy can exhibit variable or inconsistent visual responses. Some medicines may cause visual disturbances. The paediatrician or nurse can inform the QTVI and class teacher about the nature of the child’s seizures and possible side effects of medication. The QTVI can, in return, report any conclusions from her regular observations of the child.

**Feeding and digestive issues**

Poor motor control and inefficient swallowing can cause frequent chest infections when small quantities of food and drink are inhaled. If swallowing is unsafe or a child cannot ingest enough food to maintain a healthy body weight, gastrostomy feeding may be recommended. This is a procedure by which liquid nutrition passes directly into the stomach via a tube through the abdominal wall. It is no longer unusual in special schools to see a number of children being fed in this way. The class teacher and QTVI need to be aware of medical advice relating to children having tastes of food or drink, as tasting is often an important feature of a sensory lesson.

Where a school nurse or specially trained support assistant carries out gastrostomy feeding, it may be necessary for some children to be fed during lessons. This can sometimes interrupt the child’s routine, and may mean that they have nothing to do during lunchtime (on the plus side, this can present an opportunity for a session with the VI teacher!) It is preferable for children to be fed alongside their peers during regular mealtimes if possible. This has been achieved in some schools
where non-medical staff are trained to feed pupils. When a child eats orally but can only manage pureed food, the QTVI and speech and language therapist will often advise that each food should be liquidised separately so that the child will experience different flavours and colours in their meal. Their plate should provide a good colour contrast too.

Children with complex needs can experience particular challenges in relation to the regularity of bowel movements. Constipation can cause intense discomfort. A child who is experiencing this is less likely to be alert and to respond actively to their environment. The health visitor or school nurse can monitor this situation at home and at school and can make parents, the class teacher and the visiting QTVI aware of this. It can be one of the reasons why a child may fail to perform effectively at visual tasks that normally form part of their everyday repertoire.

**Cerebral palsy (CP)**

Like epilepsy and cerebral visual impairment (CVI), this condition is a result of brain injury, usually around the time of birth. Not only affecting movement, it can also impact on growth and development. Despite intensive physiotherapy, some children may develop severely restricted movement as tendons become too tight to permit limbs to stretch and relax. Children with CP often need a range of special equipment to support their posture. Physical disabilities (and associated pain) can impair access to learning. Some children may have impaired hand movements. This will impact on their tactile skills so that they are unable to use touch to compensate for their visual impairment. Others cannot access visual learning activities due to limited head and eye movements, or simply because someone has placed their chair facing the wrong way! The following example highlights joint working between the nurse and QTVI:

**Kerry**

Kerry has CP and epilepsy. She has healthy eyes but her teacher is concerned about her poor visual attention. CP affects functional vision. The effort of controlling head and eyes is tiring and is possibly the reason Kerry switches off from time to time. The QTVI or another qualified professional will carry out a functional vision assessment. CVI or visual processing disorder occurs in a high proportion of children with CP. The QTVI consults with the school nurse regarding the nature of Kerry’s seizures. She will also discuss postural support and positioning with the physiotherapist and occupational therapist. This information helps her to advise the class teacher how to improve Kerry’s visual access to the curriculum.

**Degenerative or life limiting conditions**

Children with degenerative or life limiting conditions present teachers and all concerned with special challenges. The role of the QTVI is to help the child, and the adults supporting him, to prepare for and manage visual and other changes. New skills, such as alternative ways to communicate or access information, need to be learned early so that the child can remain independent for as long as possible and will involve consultation with the speech and language therapist. It is helpful for the QTVI to consult with a medical professional in order to understand the progress of the condition.
Other sensory impairments

In addition to sight problems, some children may have a hearing and/or other sensory loss (eg impaired senses of smell and taste in children with CHARGE syndrome). Children with multi-sensory impairment (MSI) need a very high level of appropriate intervention to help them access all learning experiences. This may be provided by a specialist MSI teacher as well as other therapists.

Using communication passports for assisting with medical needs

Good communication is essential when a child’s health and wellbeing is at stake. A communication passport can help all the people involved with the child to understand their needs. This user-friendly document is produced in consultation with the child’s support professionals and family. It is kept with the child, and includes essential information. This includes medical and sensory issues, feeding and personal care, preferences, and the child’s own communication – expressions, sounds or actions that say “I’m happy”, “leave me alone” or “I’m hungry”. It suggests ways to calm the child if she is upset. Photos show how a child’s hoist or standing frame is used, their symbols or objects of reference or the special cutlery and crockery they need at lunch time.

Medical information can be included on the passport, or on a separate “All about me” profile. This might include emergency contact numbers, how to recognise and handle seizures, emergency intervention, and how to tell when the child is in pain. The vital information sheet can be printed on coloured paper for easy access.

An “All about me” profile is particularly valuable if a child is admitted to hospital or moves school. These are often times when children feel most vulnerable and consistency is especially important. It can give hospital or school staff a snapshot of the child’s needs and personality and helps them to interact confidently and appropriately. The following example demonstrates the impact a communication passport can have in helping children and young people make choices known and feel in control of a situation.

David

Following a serious head injury David has very little independent movement and cannot speak. His facial responses indicate that he understands a lot of speech and has a good sense of humour. David has some limited vision in his left eye. He can eye-point, using two large, fluorescent cards to indicate “yes” and “no”. It takes him a few seconds but his responses are reliable. This information in his communication passport helped hospital staff to communicate with him when he was recently admitted for surgery.
Medication

Almost all children who have complex needs are on medication. Administering medication to children who have little or no sight requires special consideration. Suddenly placing something that may have a very distinctive flavour or texture in a child’s mouth can be very frightening. Similarly, medications that have to be administered in different ways, e.g., by injection, by inhalation or by rubbing on the skin can all trigger an adverse response if the child is not properly prepared. Discussion between medical practitioners, parents, carers, teacher and QTVI can really help to overcome this. All can provide ideas from their particular perspective and understanding of the child. For example, a special object of reference may help a child to prepare for medical intervention. Alternatively, a special on-body sign may help to indicate a particular procedure.

The role of the nurse is to:
- ensure consent for children and young people taking medication
- record the child or young person’s preferred method of taking medication
- ensure correct consents are in place for the use of covert medication
- help support the child or young person’s understanding of their medication along with their right to refuse medication and have it later. This allows the child or young person to feel that they are in control of this process rather than the administering of medication being something that is “done to them”.

If medication is taken orally, it is important to know how a child prefers to take this. Personal taste will dictate whether it is diluted, given by spoon or a cup, mixed with a sweet drink or given with food. Discussion with a QTVI may help to identify how best a child might be able to identify medication so that they are aware of what it looks like.

The potential side effects of medication should always be considered by everyone concerned with the child. Details should always be provided in a care plan or in the “All about me” profile. These may include drowsiness, excessive thirst, or hyper-sensitivity to UV light. Some side effects will impact particularly on the work of a QTVI, especially if the session with a child always takes place at the same time after the administration of medication. Some drugs impede visual responses. If the QTVI is undertaking work on functional vision, a particular response may have more to do with the medication than the child’s true visual ability. The following example highlights the effect of medication on learning and emphasises the importance of joint working between professionals.

Andrew

Andrew is unable to control his drooling, and always has a sore chin and neck. He has recently been prescribed Hyocine patches which help to dry up the secretions. These patches can dry the eyes and dilate the pupils. If this happens, in Andrew’s case his vision may be affected. Bright sunshine could be very uncomfortable. The QTVI asks the advice of Andrew’s doctor and
ophthalmologist which she shares with Andrew’s parents and teacher so that they can observe Andrew’s visual responses and put necessary measures in place.

When supporting children with complex needs, the QTVI will often see variations in visual awareness that may indicate changes in their general health. Epilepsy and medication can affect functional vision, likewise progressive diseases, fatigue and pain. When a child is not able to describe the way they feel, it is important for any changes to be reported to the nurse, doctor or specialist.

**Conclusion**

When children have complex needs it is difficult to address each sensory, physical and medical issue in isolation. It is beneficial for each professional to understand the medical, therapeutic and educational needs of the child in order to carry out their individual area of support.

When children’s health needs are effectively managed, other therapies and interventions are more successful. In schools, staff training and a good relationship with the school nurse promotes confidence, reduces the impact of health issues and ensures that children with on-going medical conditions are fully included in the school curriculum.

**References**


**Insight magazine**

**Inspirational and practical** information on the education, health and wellbeing of **children and young people** with visual impairment, including those with complex needs.

Parents now receive **Insight** free when they become RNIB Members. Insight is also now available free to VIEW members! For details, call **0303 1234 5555** and quote “Insight offer”.