



# Medical Information Document Cerebral Palsy and Cerebral Visual Impairment

#### What is the normal structure of the eye?

The eye is made of three parts:

- A light focussing bit at the front (cornea and lens).
- A light sensitive film at the back of the eye (retina).
- A large collection of communication wires to the brain (optic nerve).

A curved clear window called the **cornea** first focuses the light.

The light then passes through a hole called the **pupil**.

A circle of muscle called the **iris** surrounds the pupil. The iris is the coloured part of the eye.

The light is then focused onto the back of the eye by a **lens**.

Tiny light sensitive patches (photoreceptors) cover the back of the eye. These photoreceptors collect information about the visual world. The covering of photoreceptors at the back of the eye forms a thin film known as the **retina**.

Each photoreceptor sends its signals down very fine wires to the brain. The wires joining each eye to the brain are called the **optic nerves**.

The information then travels to many different special 'vision' parts of the **brain**. All parts of the brain and eye need to be present and working for us to see normally.

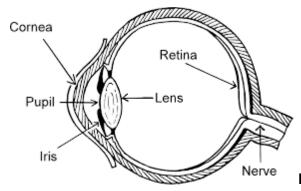


Figure 1: The Structure of the Eye

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### How we see: Beyond the Eyes

There are many different parts of the eye and the brain that need to work together in order for us to see well. The brain gets signals from the eye and sends them to the vision parts of the brain. In order for us to see it is the brain that does most of the work.

#### Seeing beyond the eyes in more detail

When we look, the picture we see travels from each eye along a nerve which connects the eye to the brain called the optic nerve. This is like a cable carrying an internet or TV signal. The signal is carried along each optic nerve and the two optic nerves come together in an area called the optic chiasm where some signals cross over. The signals from the left side of both eyes are usually sent to the right side of the brain, and the signals from the right side of both eyes are sent to the left side of the brain. The signals are sent to two main parts of the brain.

Most of the information is passed to the back of the brain, (the occipital lobes). The left occipital lobe sees the right side of the picture from the eye and the right occipital lobe sees the left side of the picture. To make things more complicated the bottom part of the occipital lobe sees the top part of the picture and the top part of the occipital lobe sees the bottom part.

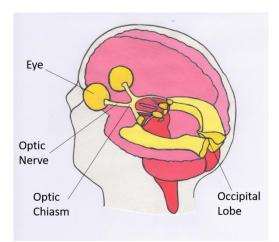


Figure 2: The Main Pathway for Information Travelling from the Eye to the Brain

Some information is sent to a central part of the brain called the brain stem. This is an important pathway for children with very poor vision as it helps them to pick up movement without thinking. It can help them to automatically move out of the way of objects heading towards them, particularly from the side.

From the occipital lobe the information is then sorted out and sent to three main other parts in the brain. Some of the information goes to the area of the brain called the posterior parietal lobes (these are near the top back of the brain). This is sometimes called the dorsal pathway.

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Some information goes to the temporal lobes (at the sides of the brain) and this is the where the visual memory is stored. This is sometimes called the ventral pathway. Information is also sent to and from the frontal lobes (which are at the front of the brain). This is the part that allows us to put information together. The posterior parietal lobes help us to see the whole picture and link up our movement with what we see, the temporal lobes help us to recognise things and the frontal lobes help us to choose what we look at and pay attention to.

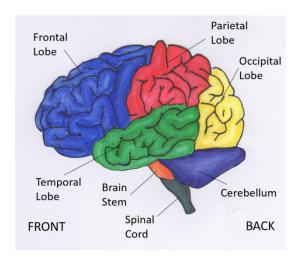


Figure 3: The Main Areas of the Brain

The visual brain is a very complex network where information is flowing back and forth all the time. All parts of the brain and eye need to work well. Difficulties with vision can occur if there is damage in or to any of these areas, systems or processes.

#### What is cerebral palsy?

Cerebral Palsy (CP) is the name for a group of conditions causing children to have a difficulty with control of their muscles and movement due to a problem within the brain. It can occur if a baby's brain does not develop normally during pregnancy, or is damaged during or soon after birth.

It can affect children's movement, coordination and posture in a wide range of ways. Different children are affected in different ways depending on which areas of the brain are damaged, or not fully developed.

Depending on how much damage there is, some children with cerebral palsy have only a mild form with minor movement difficulties, while others may be severely physically disabled.

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There are many names for different types of cerebral palsy. Generally there are three main types described, depending on which areas of the brain are damaged:

- spastic cerebral palsy the muscles are stiff and tight which makes movement difficult
- dyskinetic or athetoid cerebral palsy there are involuntary muscle tightening resulting in uncontrolled movements and spasms
- ataxic cerebral palsy balance and coordination are affected resulting in unsteady and jerky movements

Depending on which muscles are affected, some other words are often used to describe cerebral palsy:

- hemiplegia occurs when the arm and leg on one side of the body are affected
- diplegia is when both legs are affected
- quadriplegia means all four limbs, and usually the whole body, are involved

Cerebral Palsy is also described in other ways depending on how much a child can do based on their ability to move around, walk or use their hands. There are scoring systems (such as GMFCS) that may or may not be used in your area.

## Which other conditions can occur with cerebral palsy?

The brain damage or abnormality often affects other parts of the brain in addition to the movement areas so that children with cerebral palsy often can have other conditions including:

- learning disability
- seizures
- problems with speaking and communication
- eating and swallowing difficulties
- difficulty controlling saliva
- · difficulties with sleep and behaviour
- hearing impairment
- cerebral visual impairment

Children with cerebral palsy are also much more likely to need glasses than other children.

#### What is Cerebral Visual Impairment (CVI)?

Cerebral Visual Impairment (CVI) is the name given when someone is unable to see well, or can't fully understand what they are seeing, due to some parts of the brain not working as they should. As with cerebral palsy, this is the result of a baby's brain having been damaged, or not developing in the usual way. The child doesn't see well, even though the eyes are often working well. The brain is unable to make full sense of the picture the eyes are sending it.

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All children with CVI are not the same, and vision can vary from having difficulty with only one thing, like recognising faces, to having no sight at all. In most cases, once the damage has happened it does not get worse. As they grow and develop children usually learn to use their vision in better ways.

This condition used to be called cortical visual impairment.

#### What are the causes of Cerebral Palsy and Cerebral Visual Impairment?

There are many different causes of damage to the 'movement' parts and the 'vision' parts of the brain. The problem is most often present from birth, but can sometimes happen later in the child's life.

Most often the damage happens during pregnancy when the brain is developing. Damage can also happen around the time of birth. This might be due to the baby's brain having a poor blood supply or the baby having difficulty breathing. Premature babies are at more risk of damage.

Sometimes children can have a problem with both their eyes and their brain causing their difficulty with vision.

The following conditions which cause damage to the brain can affect the "movement" and "vision" parts of the brain:

- Infection (meningitis and encephalitis )
- Poor drainage of the fluid that surrounds the brain, causing pressure on it (hydrocephalus)
- Serious head injury, brain tumours or bleeding within the brain
- Stroke (cerebrovascular accident)
- Sugar and salt imbalances within the blood
- Some severe forms of epilepsy

Most children do not have any problems with their vision or their brain, even if they have had problems during pregnancy or birth.

#### **How is the diagnosis of Cerebral Visual Impairment made?**

If a child is suspected of having visual impairment, an assessment can be requested through their GP, or any children's health service already involved. Firstly, standard vision tests and an eye examination will take place in the eye clinic. Some special tests such as electrophysiology may then be organised. This test and other vision tests used at the eye clinic are explained in <u>videos here</u>.

It may be possible to diagnose Cerebral Visual Impairment at this stage. If these eye tests are normal, or the results don't explain the way the child looks at things, sees things or the way they move, then further assessments are needed. The child should then be assessed by a developmental paediatrician to see if the way they behave is due to another problem such as a learning or movement difficulty.

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If there is still no explanation for a child's behaviour, then the child should have an assessment to look at the way their brain makes sense of what they see. This involves a team of professionals, asking questions about how the child sees and watching them do different kind of activities. This is often done in a specialist clinic. There is a guideline to help with diagnosis. The steps in the guideline are explained here.

There are some recognised patterns of difficulties which can often occur together. This is due to the flow of information through the brain being interrupted or damaged. Sometimes this information flow is called a pathway. There are two main pathways for visual information:

- the dorsal pathway which links vision with movement and allows a person to see lots of things at once and
- the ventral pathway which uses vision to recognise things, work out where things are and find the way around.

Not all children's difficulties will fit these patterns.

Sometimes a type of brain damage called Periventricular Leucomalacia (PVL) can be seen on a brain scan (MRI). This is a term used to describe the scan picture but is not a condition. It tells you that some damage has happened, but not whether it affects the child or their vision.

# How does Cerebral Visual Impairment affect a child's vision?

Most young children with Cerebral Visual Impairment feel their vision to be 'normal' as they have never known anything else. They think that everyone else has vision the same as their own and do not realise that other people see things differently. How Cerebral Visual Impairment affects children can be very different depending on the child and how and where the brain is damaged. If there has been lots of damage to many parts of the brain the vision can be very poor, but the child may still see movement and bright lights. Complete blindness due to brain damage is rare. Some children may have damage to a small area only and can see very well apart from that one specific problem.

Children with CVI can have problems with:

- 1. Seeing clearly (blurry vision)
- 2. Seeing in all of their visual field (being able to see all around, some areas can be 'missing').
- 3. Eye movement ( nystagmus [see glossary], difficulty in following things or switching to look from one thing to another )
- 4. Seeing several things at once and becoming 'overloaded' with things to see ( difficulty with this can be called simultanagnosia or visual crowding )
- 5. Seeing things which move, or rarely, seeing things which don't move ( difficulty with this can be called dyskinetopsia )
- 6. Using their vision and movement together e.g. looking at something and being able to reach for it (difficulty with this can be called optic or visual ataxia)

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- 7. Noticing things and looking at them, particularly noticing more than one thing at a time (difficulty with this can be called visual inattention). This can often make the child appear to have a difficulty in their field of vision.
- 8. Recognising objects or people ( difficulty with this is called different names depending on what is affected usually it is called an agnosia e.g. shape agnosia )
- 9. Working out how close or far away things or people are from each other. This can make it difficult for children to find their way around, judge stairs when walking, or write (this is called visual spatial perception)
- 10. Being slower to understand what they are seeing

Children can have one, several or all of these difficulties.

# What can be done to help in Cerebral Visual Impairment?

There are no medicines or surgical treatments that will fix or improve damage to the brain. There are however lots of things that can be done to help children with CVI use the vision they have better.

Changing the way things are shown to them, can make a big difference to their development, learning, independence and happiness – the earlier this is done the better. It is important that they are shown things that are big enough, bold enough and close enough that they can see them. Some children with CVI need more time to look at things or may need to have them separated out to see them properly.

What can be done is dependent on the particular areas of difficulty a child has. At the time of diagnosis a full assessment should identify which areas the child has difficulty with, and what will help.

What helps is different for different children and also dependent on their stage of development.

Below are just some examples of things that can help and does not apply to every child:

- 1. If a child has difficulty with clarity of vision then making things larger or closer helps. Good lighting is important too. Simple things in school like making print bigger is easily done, or children may need supplied with a camera connected to a laptop or tablet to make things bigger. For young children coming close to them so that they can see a smile and learn about facial expression is important.
- 2. If a child has a problem with their field of vision then making sure others know where they may have difficulty helps
- 3. If children have nystagmus, allow them to position themselves where it is comfortable, looking in the direction they see best. If they have difficulty moving their eyes they may be better moving their head to follow things.

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- 4. If children have difficulty in becoming overloaded with information simplify things. Avoid patterned carpets, walls, duvet covers and floors. Keeping everything plain means they can see the thing they need to see. Organising their room at home or desk at school so they don't have to search for things in piles can help. Try not to show them something and tell them about it at the same time, ask them to look, then listen, not both at once.
- 5. If a child has difficulty seeing things which move, they need to take care on road crossing etc. They should have input from a qualified habilitation specialist. If fast movement is a problem then videoing a moving car/ animal etc on a mobile phone using the zoom function slows the movement down so that it can be seen.
- 6. If a child has difficulty coordinating vision and movement then they often find feeling their way helps. Examples of this can be by running their heel down the back of the stair when walking downstairs, spreading their hand widely to reach for something or using their other hand to guide them to put a cup back on a table
- 7. If a child has difficulties noticing things (visual attention) then calling to them first to get their attention and pointing helps. Highlighting doorways with bright tape can be useful so they notice them.
- 8. If a child has difficulties with recognising particular things like shape, faces etc they need to learn other ways to do this such as learning shape through touch.
- 9. If a child has difficulties with visual spatial perception then they need taught ways to remember routes and judge space. They may need the help of a paediatric occupational therapist as well as a qualified habilitation specialist
- 10. If a child takes time to understand what they see, show them things for a long time. Don't take them away quickly thinking the child isn't interested in them.

#### What can be done to help children with visual impairment?

We use our vision to get around, learn new things and to meet other people and make friends. Children who have visual impairment may need some extra help to do these things.

It is important to know and understand what your child sees so that you can give them the help they need. Young people themselves need to understand how and why they may see differently from others.

If glasses, contact lenses or a Low Visual Aids (LVA) have been prescribed, it is important that these are used. These will help your child see more clearly and make sure the vision parts of the brain grow and develop correctly. Even if your child's vision is very low, try to get them to wear their glasses if prescribed. This will help to give as clear a picture as possible to help get them interested in looking.

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Even if a child has very poor vision many useful and practical things can be done to help. All children who have a visual impairment should have an assessment of their needs by a qualified visual impairment teacher and a qualified habilitation specialist. They are professionals who can give advice and support your child in learning, education and in practical and play activities.

#### Where can I find more information on Cerebral Visual Impairment?

There are many books, websites and papers on this subject and not all those working in the area agree on everything about this complex condition. It is best to talk directly with the specialist health staff, qualified visual impairment teacher and qualified habilitation specialist involved with your child to discuss his/her particular difficulties and how to help them.

Useful information can be found in the following:

www.cviscotland.org

www.cvisociety.org.uk

www.rnib.org.uk/insight-online/supporting-children-cerebral-visual-impairment

Other general information on low vision is available from national organisations such as Guide Dogs and RNIB, and from your local visual impairment society (these are listed on the <u>VINCYP website contacts</u>).

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#### NOTE

This guideline is not intended to be construed or to serve as a standard of care. Standards of care are determined on the basis of all clinical data available for an individual case and are subject to change as scientific knowledge and technology advance and patterns of care evolve. Adherence to guideline recommendations will not ensure a successful outcome in every case, nor should they be construed as including all proper methods of care or excluding other acceptable methods of care aimed at the same results. The ultimate judgement must be made by the appropriate healthcare professional(s) responsible for clinical decisions regarding a particular clinical procedure or treatment plan. This judgement should only be arrived at following discussion of the options with the patient, covering the diagnostic and treatment choices available. It is advised, however, that significant departures from the national guideline or any local guidelines derived from it should be fully documented in the patient's case notes at the time the relevant decision is taken.

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