

## Cortical Vision Impairment

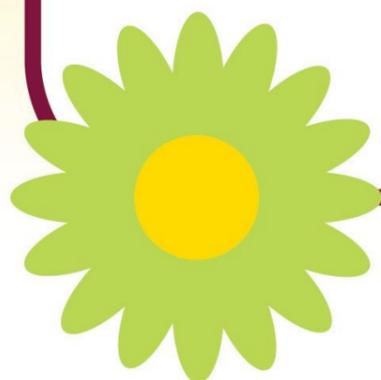
### Features of CVI which may be noticed in people living with CDKL5

May have a deficit in one or more quadrants of the visual field. So a failure of mouth opening for an oncoming spoon may relate to a lower visual field deficit. There may be a lack of vision or lack of attention on one side or the other and with reaching for objects to the side but not straight ahead. This may also appear to be generally uncoordinated movement. There may be one upper quadrant of the visual field that can be used to advantage.

- Looking away from people/objects in order to 'see' them - this is often seen by parents and carers gives with the typical CDKL5 sideways glance.
  - Vision seems to be variable and may change on an hourly or even a day to day basis.
  - Inability to fix on objects for any length of time.
  - Irregular eye movements.
  - Lack of response to objects placed on a 'busy' background which the person may respond to against a plain, contrasting surface.
  - Eye movements not made independently of head movements.
  - Difficulty seeing objects unless moving or in some people, unless objects are still.
  - Lack of response to faces/facial expression.

### Simple strategies to help children with profound and multiple learning difficulties include:

- Notice what lighting conditions the child prefers, some prefer darkened areas and some brighter ones.
- Understand that attention can only be given to one or two things – often only one thing at a time.
- Ensure they are comfortable, comfort helps attention.
- Eliminate background sounds and other distractions.
- Use one object at a time and not many in total – less really is more!
- Provide a meaningful experience at the right speed – use the KISS principle! (Keep It Slow and Simple)
- Give the child favourite objects to begin with then watch and wait – most of all give them time to respond – don't be tempted to 'fill the space'.
- Remember responses will vary – tiredness, ill health will all make a difference.
- Remember the child will be working very hard processing information and will tire easily –small activities, little and often works best.



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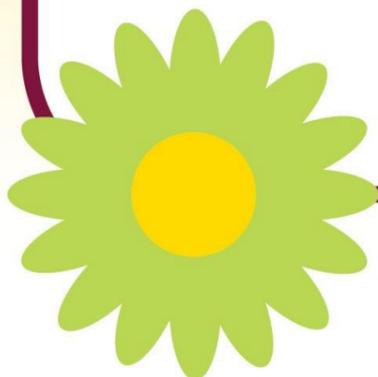


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- The child will also find it easier to process visually, when they are not required to look at busy backgrounds. Plain is best, therefore try to ensure that items/toys are placed on plain, high contrast backgrounds so they are more easily recognised and processed by the brain. Allow the child lots of time to respond (it may take many, many minutes).
- Remember they may look, then look away before returning to the item.
- Give the child the opportunity to handle lots of different textured toys and objects.

Technology may make a great difference to a child's ability to communicate and access learning, from switch technology, to technology to develop visual skills using appropriate software or apps. Much is now available which can help a child with CVI. It is important that technology is carefully selected so that it can develop skills – some children will benefit from using simple, repetitive tasks, in particular children with multiple disabilities in order they can best learn to respond and progress.

**Special thanks to the Cerebral Visual Impairment Society UK for allowing us to reproduce their material. For more information about CVI and strategies to help you with your child or adult living with CDKL5 please visit [www.cvisociety.org.uk](http://www.cvisociety.org.uk).**



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