Hello from CVI Scotland, which is short for The Cerebral Visual Impairment Society of Scotland.

CVI Scotland is run by parents for parents, supported by an amazing group of experts, who want to help us to help you.

We have written this guide for people caring for a child with CVI, but it is useful for everyone, whatever their age, if they have CVI or know someone with the condition.

The effects of CVI upon each child, are unique so your child is different to all other children with CVI.

CVI does not have a medical treatment*, but once you understand which of the CVIs your child is affected by, and to what degree, there is a HUGE amount you can do. We will show you as much as we can.

You will hopefully have many different people helping you, which may include doctors, therapists and teachers.

They are all experts, but they do not know your child - you are the most important expert your child has.

We think that your child will get the best support by combining your expert knowledge with the advice and knowledge of those helping you.

In this guide, we don’t try to explain what CVI is. Your child’s CVI is unique to them, and it would take too long to try to cover all children, that’s why we’ve created the website. The website is written for parents, so that you can learn about CVI one step at a time, and apply what you learn to your child.

As you learn, you will begin to see, hear and understand the world the way your child does.

This can be difficult, and at times stressful and frustrating, and it takes time and dedication. Yet it is also satisfying, fulfilling and empowering. Seeing how our hard work helps our children across all levels of their development and brings them happiness and fulfilment, is the biggest reward we could ask for.

Take it slowly, take control, and enjoy!

Best wishes

The CVI Scotland Team

*Except for seizure disorders, if present, which respond to treatment, which can lead to improvement in vision
This is very important to understand, because...

...in people with CVI, the mental picture the brain makes and the real world may still appear the same - but they aren’t! This is what causes the difficulties.

So for children with CVI, the match between the real world and the world their brain creates is inaccurate. For some who are only mildly affected, vision is a bit more challenging, like when learning to read, or playing sports. For others it is more severe, and can be up to a point where the real world and the mental picture made by the brain, might be very different. In this guide we are going to call this the child’s altered world.

Every child with CVI is different. CVI can make learning very difficult, because the unique challenges are not recognised nor understood.

Vision problems because of the eyes are called ocular visual impairments (OVI) and these are very different to CVIs. For OVI the shape of what is seen is blurred, but the location and timing of the mental imagery is likely to be close to reality. On the other hand, with CVI, the altered world leads to different difficulties that need different approaches. If this is not understood, it can lead to confusion, tension, stress or boredom, because learning is harder or even impossible.

You need to make sure all support not only matches the needs of a child with CVI, but also matches the unique needs of your child.

If you are not sure – ASK.

The other senses

Some people with CVI also have difficulties with one or more of their other senses of hearing, touch, taste and smell. For example, one thing we hear a lot is about children who struggle to look and listen at the same time. When a child with CVI has difficulties with the other senses, which can be mild to severe depending on the child, it can be easier to think of CVI not in terms of what your child sees, but in terms of what they experience, and how they experience it.

It is increasingly accepted that each child with CVI is different and you need to find out and learn how CVI affects your child, and be prepared to explain this information to others on behalf of your child.

Avoid labels

Where something is given a label, it creates a group. But approaches to help can tend to be around the label not the child (sometimes called generic approaches). We repeat over and over - YOUR CHILD IS UNIQUE - the approaches need to be relevant to your child, not any label they have been given, which may include

- learning delayed/developmentally delayed
- behavioural difficulties
- distracted
- clumsy
- CVI!

Yes, CVI is a label too - it is the group name for many different brain conditions that affect vision, and can affect anyone of any ability of all ages from premature babies to the elderly.

There are no quick fixes, it can only be a journey

We think the best way to learn is in steps. Learn a bit, then see how it fits with your child, and when you are happy you have understood, move onto the next bit. You will find that all the different ideas and approaches that work interconnect.

You will never know it all, no one does, but as you soon see your learning, turning into learning for your child, you will be hooked - like we are!

Let’s get started...

What’s the Point (purpose)?

When starting to understand CVI it is important not to get lost and waste important learning time on things that are just not relevant to your child. We have created three general groups (below). If what you are doing fits into at least one of them, then your child should benefit. These groups are:

1. Learning: The average child spends only 15% of their time across a year at school - that’s a lot of learning time outside of school. Much learning takes place at home. Learning is about understanding the world.
2. Independence: To help your child do things for themselves. This varies from child to child, and for some it will be learning to communicate likes and dislikes, to feed and to dress themselves. For others it will involve learning the skills to live a fully independent life.
3. Social Relationships: To help your child develop friendships and lasting relationships, which can be more difficult because of CVI.

How can you help?

You can help your child in many ways, and one is by making sure everyone else helping your child understands their unique needs.

You may be working with many different people with different jobs.

Parents need to – Teach...the many people who help your child:

- how CVI affects your child
- what your child does and does not like
- explain your child’s support to date, including their learning, and whether this has been difficult.
- explain any behaviours your child may have.

No one knows your child like you do.

Over time, as you learn more about CVI and how it affects your child, you will speak with increasing confidence.
Parents need to – Ask...if you are unsure of anything.

Ask

We say this a lot, and part of our journey has been to find our voices and to have the confidence to ask when:

- We need more explanation
- We have a suggestion
- We think there might be a better/different approach

Our website tries to explain CVI. It includes many suggestions for support that you can match to your child.

There is a lot to learn and it takes time. We start with eight simple points, which we think you, and everyone working with your child, need to understand:

8 things everyone needs to know...

1. Everything you can do, you have learnt. Like learning to talk, learning to dress and feed yourself, learning to make friends, learning what music you like, and learning to read. Learning doesn't just happen at school!
2. We learn from what happens to us. We do this with our five senses - sight, hearing, touch, taste and smell.
3. If something is not visible to us, we can't learn from what it looks like unless it is made visible. If something can't be heard we can't learn from what it sounds like unless it is made accessible. This is the same for the other senses.
4. There are a lot of reasons why things may not be seen or heard. These can be found on this website.
5. Whenever you are with a person with CVI, you need to think about what they can see and understand, not what you can see and understand. This means you must know and understand how CVI is affecting that one person, as this is different from every other person with CVI.
6. The more you make things accessible, relevant and understandable, the more the person with CVI will learn.
7. Just seeing or hearing something doesn’t mean you understand it. If you see something new it often needs to be explained to be understood. This means that you will probably have to do a lot of things differently to help the person with CVI learn, and that is at home, at school and out and about. And this applies not just to you, but to everyone around the person with CVI.
8. You and the person with CVI you are with, will both get out what you both put in.

The more you learn, and the more you help the person with CVI to learn, by making their world more visible, accessible, understandable and memorable, the more they will progress and everyone will be happier. Happy people learn best!

Professionals need to listen to you

In putting together this guide, we have spoken to lots of different people doing lots of different jobs, including teachers, therapists and doctors. They all agree that listening to parents is one of the most important parts of their job.

Remember that you are the expert when it comes to your child.

Other People & Other Stuff

In the sections below, we look at some of the different people who may be involved with your child's care.

All these people should be qualified in their area of expertise, but not necessarily CVI, and definitely not your child.

Many professions have chosen to learn about CVI, which is wonderful, but you should not take this for granted and always ASK. At present many professionals have yet to master the subject.

Many people have training working with people who have issues with their vision, but not all visual impairments are the same.

Remember your child’s altered world - if the people working with your child don’t understand this, help them by explaining, and directing them to our website for more information. That way everyone learns.

We have to warn you again that some approaches for children with visual impairments are not suitable for children with CVI - even the approaches for one child with CVI may not be right for another child with CVI. Your child with CVI needs their own approach, to help them learn.

We asked some parents if they had any tips or advice they wanted to share with you to help build a good working relationship with the many people who support your child - here's what they said:

• Remember they want to help, even if you disagree. By always being positive and seeking to understand each other, often we both learn something new, that helps my child.
• If you take the time to really build on this relationship, that person will be there to support you and your child when needed.
• Build a team! The more people your child has working with them, who understand them of course, the better - this takes time but is really worth it.

We have experienced both good relationships with the people who support our children, and some that cause problems - build on the good relationships, and work on the difficult ones, your child will benefit, as will you.

Doctors & Diagnosis

The cerebral visual impairments are medical conditions, and that means they have to be diagnosed by a doctor. In many cases an ophthalmologist (eye surgeon) will diagnose CVI, but some specially trained paediatricians and other doctors may diagnose too. Other professionals who may help with the diagnosis may include vision specialists such as optometrists, orthoptists and specialist teachers of the visually impaired.
The team you see should ideally give you a breakdown of which cerebral visual impairments your child has.

Doctors’ appointments tend to be short so there is only a limited amount a doctor can learn about your child in that time. Diagnosis is just the start of your journey.

Unless a seizure disorder like epilepsy is affecting the visual impairment, there is no medical treatment for CVI, and your child will normally be referred to your local authority’s visual impairment service.

If you think your child may have CVI, but there is no diagnosis, you need to find out the process of medical assessment in your area.

**VI (Visual Impairment) Support Services**

Working to find out your child’s pattern of visual impairments and the difficulties and behaviours they cause comes next. This is beyond the diagnosis, it is characterisation.

VI support needs are different for different children, depending on how old your child is, the needs of your child. Also, where you live may make a difference, as the service can vary from area to area.

In the UK, once a child has been referred to the VI Support Service (which can have different local names) normally a specialist teacher will arrange to meet you and your child and discuss their support needs. This teacher would normally have an additional qualification specifically in teaching children with visual impairments (sometimes called QTVI or TVI).

Unfortunately, we know that not all children with CVI can get support from their local VI Support Service. This is because some areas have a requirement that the child’s vision is below a certain level of clarity to get support. This level is measured by visual acuity, which is the level a detail we can see (the letter board in the optician’s room measures visual acuity).

Many children with CVI have very good visual acuity, but their CVI creates other visual difficulties. You need to find out if your child can get support from the VI Support Service, but if they can’t, don’t worry, there are lots of other places where you can get help.

Most charities supporting children with visual impairments we have spoken to have said they support CVI, even where the child has good clarity of vision. Some charities can provide a type of support called habilitation (see below). This is not given by a VI teacher, but by a specialist who has training in visual impairments, and who can be extremely helpful and supportive.

You must make sure everyone helping your child understands their unique needs.

If your child is not learning, rather than thinking they have learning difficulties, think and find out about what needs to be done so that they can learn.

Children with CVI often do not learn, simply because things are not made learnable for them. You can’t learn what something looks like if you can’t see it, or learn what something sounds like if you can’t hear it.

It seems like a silly and obvious thing to say, but only what is accessible can be learned!

Here are just a few examples of learning not being learnable for children with CVI:

- I can only see a small part of it, so it doesn’t make sense to me
- I can only see a small part of it, and it isn’t the same part I saw before so I don’t realise I’m looking at the same thing
- I can’t see it because there is something else I can’t stop looking at
- I can’t see because of the noise
- I can’t hear because I am trying to look
- I can’t see it because it is moving too fast
- I can’t learn because there is too much going on around me and nothing I see or hear makes any sense
- I can’t learn because I am frightened of things coming towards me

Think Why?

- If your child is not learning, think why? A learning delay is not the answer to why a child does not learn. That’s like asking someone how they broke their leg and being given the answer, because their leg broke. With your growing knowledge of CVI and your child, think why? What does your child find most difficult and what could be the reasons?
- Where your child is learning, again think why? What is coming together well so that your child can learn? How can you use this knowledge in other places and areas?

Then tell everyone - each time you work out something new, make it a conversation and explain it to the other people helping your child.

**School**

Your child may be:

- in a mainstream school and not needing learning support
- in a mainstream school with additional support
- in a special unit in a mainstream school
- in a school for children with special needs
- in a school for children with visual impairments
- home schooled
Like all children, your child has a right to be happy and learn, wherever and however they are educated. If they are not, you need to be their voice and fight for this right.

School covers the journey to and from school, time in lessons, time between lessons, time playing and eating, and other activities like sports and trips. That is a lot for a child with CVI to cope with, but often only little changes need to be made so that school is enjoyable and your child can learn.

This is where having really positive relationships with different people helping your child comes in very useful, as then you can all work together as a team.

**Habilitation / Rehabilitation (Orientation and Mobility)**

This is a specialist area helping people with visual impairment be more independent. There are different names for this role including orientation and mobility specialists.

Some of the reasons children with CVI find it difficult being out and about, are explained by this mother, who told us that her daughter could walk, but often would suddenly become frightened, and she did not like going anywhere with people she didn’t know. The mother wrote:

> "Sometimes she could walk happily for half an hour, other times she would fight not to go out, or suddenly start screaming. We realised there were a whole load of different things going on at the same time. If a car passed, especially a noisy car (or worst a motorbike) she would throw herself to the floor. For less loud things, like someone passing us with a pushchair, she would easily become distracted and stop and sort of lose where she was and what she was doing. Sometimes she would see something, shiny metal railings are a particular favourite, and she would have to stay and feel them and look at them, and refuse to move on. We use (for everything, not just this) an approach of taking things one thing at a time, one step at a time, and that includes allowing her time. The metal bars need to be processed before she can move on, it is part of the enjoyment of her walk. We try to go to quiet places, and if we are in busy places, we go for shorter periods of time, and build everything up, one little step at a time, at her pace, as she actually loves being out and about, but only when she feels safe."

We have separated our advice into two categories - a) children born with their cerebral visual impairments, and b) children who acquired their cerebral visual impairments.

**a) Children born with their cerebral visual impairments who need habilitation support**

One of the key areas of habilitation is mobility, that is getting around safely and independently. Habilitation specialists teach some children how to do this using a white cane. Habilitation specialists are increasingly aware of the needs of children with CVI, but will not at first know your child. Some children with visual impairments due to their eyes are able to use their other senses (like touch, feeling the white cane or hearing, listening to their surroundings) and learn to get around safely this way.

CVI is different. For many with CVI, they can see things, but what they see may not always be very useful, or may be confusing or even overwhelming. It can also be difficult to deal with two things at once for the child with CVI, so relying on spoken instructions or the surrounding sounds may not help, nor may a cane. On the other hand, letting the child explore and learn about their surroundings, building up step by step may prove more effective.

We have listed a few common reasons why CVI can make getting around difficult, you can find out more about these conditions on our website.

#### Lower visual field impairment

This is common with CVI, and varies in severity. Typically affected children don’t like going down things, like stairs and slides (which the child may be happy to climb up, but will only go down head first because they can see this way using their upper vision). They dislike uneven ground and often trip over obstacles or bump into things that are low down. Some children may not be aware of their feet as they walk. A child cannot easily learn to avoid hazards in a part of their visual field that does not exist for them.

**Looming**

Children with CVI can find it difficult to learn how big and far away things are, especially when they are moving, and it’s even more difficult when they are moving quickly.

When things are moving quickly, they may only become visible to your child when they slow down, so they may appear to spring out of nowhere.

When a child can’t judge distance, things that may be far away in the real world, can for some children with CVI feel as if they are very close – and could even hurt them. When the child is moving, they can become very anxious, particularly in busy noisy places, but even a car driving past in the opposite direction can be enough to cause a significant fright. Imagine a car mounting the pavement and driving at you, full speed - when you can’t judge distances and things are moving, this is what it might feel like - certainly from the way people describe their child’s reaction, which is often terrified, it seems as if they feel the same level of fear.

**b) Children with acquired cerebral visual impairments (needing rehabilitation support)**

Anything described above in a) can cause difficulties, plus, you need to think of the skills your child had before their injury, and how these have been affected by their injury. For example, if your child could walk, play sports, catch a ball, etc. Things your child could do, maybe play football, they may well still think they can do, and want to do, but it may be much more difficult for many reasons. A degree of re-training may be needed, or possibly different choices may need to be made. This will be different for every child.

Habilitation/rehabilitation extends to all independent skills, from dressing to being out and about and enjoying trips and holidays.

For many, the habilitation/rehabilitation specialist remains with the child for many years, making this a very important relationship and one well worth investment. From our own experiences, we have found that when we take the time to explain our child’s unique challenges, their specialists have tried very hard to find ways to help and accommodate these.

We learn from each other – the way it should be.
Therapies

Your child may need support from different therapists, including:

- Speech & Language Therapists, sometimes called SALTs, who help with developing language and communication, and feeding, eating and swallowing.
- Physiotherapists
- Occupational Therapists
- Dieticians

Therapists are often linked to a medical service and work with the family, doctors and teachers. Your child’s CVI may mean that the therapist needs to use a different approach to that needed for other children, even other children with CVI. You need to explain your child, and work with the therapist to agree the best plan. Your doctor can help and support you with this if needed.

Language & Talking

There are many reasons why some children with CVI do not learn to talk, here are just a few:

- To name something, for example a ball, it has to be consistently recognisable, and with CVI vision can be inconsistent, so the word may not be labelling the experience of seeing a ball
- Many with CVI struggle to listen and look at the same time, so may be unable to match a word with an object
- Many with CVI are unable to concentrate on more than one thing at a time, so to learn a new word with a new object or experience is too difficult

We go into more detail on the website, but rather than consider a child non-verbal, instead think ‘has yet to learn language and to talk’, then think about how language can be made learnable.

At CVI Scotland we are of the view that effective communication is one of the most important skills all children with CVI need to acquire.

Music & Colour

For many children with CVI, particularly the more severely affected, music is often easy to remember and recognise.

A child may respond to a well known nursery rhyme, and try to join in, or relax.

Where a child recognises something, that shows they have learnt it, successfully. This means music can be used to learn other things, like how to be in groups of people, or learning numbers using number songs. The potential to learn using music as a tool for learning is huge.

For a profoundly disabled child with CVI, being inside a coloured tent can be a completely liberating experience, but most children with CVI will benefit from time in a single coloured environment, to reduce the demands on their visual brain by eliminating clutter and pattern.

These topics may not be well known to the people helping your child locally (for more information we feature them on the website). You can try such ideas out at home to see how your child responds, and if the outcome is positive, tell everyone else!

Behaviours & Emotions

If their lives are often confusing, and difficult, stressful and sometimes frightening, it follows that some children may develop challenging behaviours, these might include:

- Not liking changes to routines, may lead to refusing to go to new places, meeting new people, eating new foods, or watching a new programme.
- Some children use physical behaviours like biting, pinching, scratching and hair pulling
- Some children hurt themselves including banging their heads on the floor
- Some children prefer to be alone rather than in the company of other children

We see these behaviours as being our child’s way of trying to communicate something with us, maybe that they are feeling worried or sad or scared. And then we try to work out why, and what we can do to help them to feel more secure and happy.

There are people who specialise in supporting children with challenging behaviours, including autism, but not many will have experience of the unique needs of a child with CVI, or your child.

We say it again, you have to become your child’s voice and expert. Explain each of your child’s behaviours, and you may find the people who help children with challenging behaviours may have some useful ideas. These people may include clinical psychologists, psychiatrists, psychotherapists and counsellors.

Back to you

It probably feels as though we are putting a lot on your shoulders, but you are not alone, we are a large community.

We are a community pushing for change.

The more of us supporting our children through explaining their unique needs to those that help them, means that more and more people are learning about CVI.

CVI is the leading cause of visual impairments in children in economically developed countries including Scotland and the UK, and it is common elsewhere.

We need to help people learn, because our children are the best sources of information. So in the same way we are hopefully helping you, we hope that you will help too, by taking the time to learn about how CVI affects your child, and sharing that knowledge with the professionals working with them.
**Where to start?**

Start with the first step!

Think of the things your child finds difficult, or upsetting, or confusing, and pick one. It could be around learning, or friendships, or maybe eating.

Then try to look at it from the perspective of your child, and try to look at it in little steps.

Consider this cycle as an example.

Here, the same thing is difficult over and over again, and is just going to get harder and more stressful for everyone. Think of your child, and why this is difficult, with what you are learning about their CVI's. Think what steps need to be taken to help them learn?

These steps may help guide you.

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### Learning Steps

- Identify the fears
- Remove the source of fears
- Understand your child’s world
- Help them make sense of what is around them
- Slowly, one little step at a time
- Your child always in control
- Your child NEVER frightened
- At your child’s pace
- Start to explore
- Start to learn

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And consider the new positive cycle of learning.

There is no quick fix, your child will gradually learn and try things for longer, but they will be in a positive cycle of learning rather than a negative cycle of challenges.

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**CVI Scotland Website - Where to start?**

What is CVI? (http://cviscotland.org/documents.php)

These sections explain cerebral visual impairments, using a step by step approach of learning and understanding. Not everything will be relevant to your child, but it is worth reading as sometimes children are affected by areas people have not realised before.

There is a growing Support section which has been written for parents, we do not expect you to be experts in CVI (yet!) but we know you are the expert of your child - that is all you need to start.

[www.cviscotland.org](http://www.cviscotland.org) | [info@cviscotland.org](mailto:info@cviscotland.org)
Join us on our journey, sharing and developing our understanding of CVI...

You are stronger as a team
You! It has to be you
Your child is unique
Learn to see their world
Switch fear to learning

Cerebral Visual Impairment Society of Scotland
A Scottish Charitable Incorporated Organisation (Registration SC046836)