What is cerebral palsy?

This booklet will help you to have a better understanding of the physical and medical aspects of cerebral palsy. We hope it will be a source of information to anyone who wishes to know more about the condition.

What is cerebral palsy?
Cerebral palsy (CP) is a term used to describe a disorder affecting body movement and muscle coordination. It is caused by damage to one of the parts of the developing brain which controls and organises a person's movement and posture. Because of this messages between the body and brain are 'scrambled'.

No two people with CP will be affected in the same way. For some people the effects will be very mild. For others they can be severe or profound with many variations in between.

How is it caused?
The damage to the developing brain can happen before, during or after birth and is usually diagnosed before the age of three. Almost 50% of children with CP are born early. Small preterm (early) babies have vulnerable brains which may haemorrhage (bleed heavily). This is because of the immaturity of the developing brain and the vulnerability of the tissue in the brain. Other causes include:

- the baby's brain not forming properly, often for no apparent reason
- lack of oxygen before, during or after birth or damage during delivery
- a genetic disorder which can be inherited
- an infection in the mother during the first few weeks of the baby's development in the womb
- an infection (e.g. meningitis) contracted after birth
- an accident, such as a car crash, causing head injury (This is known as acquired CP).

Important facts about cerebral palsy

- CP is not contagious.
- The damage to the brain is not progressive (it will not get worse).
- Having CP does not automatically mean having a learning disability.
- When CP is first diagnosed it is difficult to predict what an individual child's abilities will be.

Who can get cerebral palsy?
CP can happen in any family. It affects both sexes, although slightly more males than females have CP. Some risk factors are well-known, such as extreme prematurity, low birth weight and multiple births. The risk of CP is 5
times greater with twins and 18 times greater with triplets. However, it is not usually possible to say which children are most likely to have CP.
How many people have cerebral palsy?
CP affects approximately 1.5 – 2.5 children in every 1000 live births in the world.
Today, more sophisticated medical care means that many more premature babies are now surviving. Over the last few years the number of people with CP who have profound and multiple difficulties has increased. There are no accurate figures available for the number of people with CP in Scotland, although figures are starting to emerge through the work of research groups in Scotland. Estimates put the number at around 15,000.

What are the different types of cerebral palsy?
There are three different systems within the brain involved in controlling movement. Impairment can happen in one or more of these areas. The type of CP which results depends on which area of the brain is most affected. There are four types of CP:

- **Spastic cerebral palsy (spasticity)**
  This is the most common form of CP. "Spastic" means "stiff" and people with this type of CP have tightness or stiffness and weakness in some muscles. This causes degrees of difficulty in moving the body, which may be mild or severe. People with spastic CP have a tendency to remain in certain positions and also to develop shortening of some muscles. This can sometimes limit the movement of joints.

- **Athetoid cerebral palsy (athetosis)**
  People with this kind of CP develop certain movement patterns because of difficulty in controlling their muscles. This causes them to move a lot. It is far more noticeable when the person is excited or trying to do something. Their speech may be hard to understand because they have difficulty controlling their tongue, breathing and vocal cords.

- **Ataxic/hypertonic cerebral palsy (ataxia)**
  People with ataxic CP experience problems with balance and coordination. This is due to difficulty in controlling movements of the trunk, head, legs and arms. Ataxia affects the whole body and when walking, they will probably be very unsteady on their feet. People with ataxic CP are likely to have shaky hand movements and jerky speech.

- **Dystonic cerebral palsy (dystonia)**
  Someone with dystonia experiences rapid changes in body tension or tone. This means that when someone intends to change their position then their muscles become very tense or very floppy.

Sometimes it may be difficult to know what kind of cerebral palsy a person has, as it can be a mixture of the above four, if more than one of the movement systems is impaired. There are three commonly used descriptions of ways cerebral palsy affects different parts of the body-
- hemiplegic CP means that either the left or right side of the body is affected.
- diplegic CP affects mainly the legs (although the arms can be affected to a lesser extent).
- quadriplegic CP affects both arms and legs with the arms more severely affected than in diplegia.

What are the physical effects?
As stated earlier, no two people will be affected in exactly the same way. This is because the effects of CP vary according to how much damage has been done to the developing brain. People with CP have difficulty controlling some or all of their movements. In some people this is hardly noticeable, while others might have difficulty talking, walking or using their hands. Some people will be unable to sit up without support and will need help to do most everyday tasks.

A person with cerebral palsy may have some or most of the following features, to a greater or less extent:

- slow, awkward or jerky movements
- stiffness
- weakness
- problems with central balance control (floppiness)
- unwanted movements
- the start of one movement resulting in other unwanted movements
- the development of certain patterns of movement.

The results of these difficulties may mean a delay in achieving the "milestones of development". In other words a child may be slower than average in acquiring physical skills such as hand control or learning to walk. Some people who are severely affected may never develop the most complex of these skills. However, good therapy, support and education of parents to know how to assist their child, can help progress in early years.

Different people involved with treatment
Depending on the severity of the condition, the person with CP might get treatment from different therapists. The three most common for people with CP are:

- physiotherapists- will aid someone’s mobility using exercises and manipulation to develop their maximum physical function.
- occupational therapists- will aid someone in becoming more independent in their everyday life by recommending certain equipment and/or adaptations.
- speech and language therapists- will aid and support someone who may have communication difficulties and/or problems with chewing and swallowing. They may recommend communication aids.
Some people with CP may need no or little treatment.

**Adults with cerebral palsy**
The damage to the brain does not worsen as an individual gets older. However, over time certain of the physical effects, such as muscles tightening and shortening, can produce other problems such as joint stiffness. This can cause discomfort and hinder a person's activity, if ignored.

**Are there any other problems associated with cerebral palsy?**
Certain difficulties are more common in people with CP:

- **Eyesight**
The most common visual impairment is a squint, which may need correction with glasses or an operation. More serious visual impairments are much less common. Visual field defects are sometimes present and should be tested for. This means that the part of the brain that is responsible for understanding the images the person sees is not working properly. The eyes may look healthy when examined, but the person will not be able to see normally.

- **Hearing**
A small number of people with CP have hearing impairments which cause difficulties with speech and language. Some children with CP develop "glue ear" (catarrh in the year) or other ear infections. This can cause a hearing impairment. This, in turn, can make learning to speak more difficult until it is treated.

- **Spatial Perception**
Some people with CP have difficulty in perceiving space and relating it to their own bodies (for example, they cannot judge distances) or thinking spatially (eg visualising a three-dimensional building, being able to tell right from left, understanding the concepts of "in", "on", "under ", etc). It may affect people's ability to do things like position clothing, dressing or making it more difficult to learn maths, reading and writing. This is caused by an abnormality in the part of the brain and is not related to intelligence.

- **Speech and Language**
Some people with CP have no speech. Others have difficulty speaking. Some have difficulty controlling movement, which means that the muscles in the mouth, tongue, palate and voice box are affected. This can make speech sound unclear. However, many children with CP learn some kind of verbal communication. A wide range of equipment is used by those with or without speech to the aid communication. This includes computers which can be programmed to produce words and phrases. Other systems use special signs and symbols e.g. Bliss, Makaton, Signalong. These are known as **Alternative Augmentative Communication systems (AAC)**.
• **Chewing and Swallowing**
Sometimes chewing and swallowing is difficult because of problems controlling the mouth muscles, lips and tongue. An early sign may be difficulty with sucking. Eating is sometimes difficult for people with CP. This can be called dysphagia. They may also have a reflux (food or drink flowing back up to the throat).

• **Epilepsy**
Around one in three people with CP have epilepsy. It is impossible to predict whether or when a child may develop seizures (fits). Some children start to have them when they are very young, others in adult life. Epilepsy can often be well controlled with medication.

• **Dyspraxia**
Some children have difficulty planning motor movements or doing apparently simple tasks like dressing. This is due to difficulties in parts of the brain which organise movement and spatial awareness. These children may be labelled "clumsy" or have learning difficulties at school, particularly relating to maths. Activities like skipping, running or climbing (known as gross motor activities) are very difficult. These children can walk quite well but will often trip or will fall. Special therapy programs can help children with dyspraxia with their motor organisation and teach them to dress themselves. These programs can supplement learning programs at school.

• **Other physical difficulties**
Some people with CP may have some other difficulties. These could include:
- a tendency to be chesty
- constipation
- chilblains
- difficulty controlling body temperature
- difficulty in putting on weight
- obesity.
In most cases these difficulties can be reduced or overcome. Health visitors, paediatricians, therapists and others can advise.

• **Intellectual Ability**
It is often assumed that people with CP who are unable to talk, or have difficulty controlling their movements, have a learning disability. This is not always the case and should never be assumed. CP does not necessarily affect intelligence, though some people might have a learning disability. The degree of speech and movement a person has does not indicate their level of intelligence.

• **Specific Learning Difficulties**
Some people have difficulty learning to read, draw, or do arithmetic. This is because a particular part of the brain is affected. If the problem is out of proportion to a person’s general intelligence, it is called a specific learning disability.
Can cerebral palsy be prevented or cured?
We don’t know enough yet about how and why CP happens to cure or prevent it. However, because of improvements in medical care before and during birth, fewer babies have been born with certain types of CP. Ongoing research, particularly around prematurity where the incidence of CP is high, is helping to reduce the level of brain and lung damage and visual impairment.

Research into improving mobility is also being carried out. Although brain damage is not reversible there are many treatments and therapies which can help people with CP. Equipment such as splints to help with walking, special buggies and wheelchairs, seating and standing frames, computers and much more can be provided to build on and support people’s abilities.

Many adults with cerebral palsy lead independent lives, with or without support. Many children with cerebral palsy attend mainstream schools and go on to further and higher education. Attitudes towards disability are changing all the time-for the better.

About Capability Scotland
Capability Scotland is the country’s leading disability organisation working for a just Scotland. We work with children, adults and families living with disability to support them in their everyday lives. Capability Scotland works with disabled people, their families and carers for a just Scotland by influencing policy, legislation, practice and attitudes. We voluntarily fund a national disability advice and information service with a particular focus on cerebral palsy.

Advice Service Capability Scotland (ASCS) produces a range of fact sheets on cerebral palsy and can give up-to-date information on other CP organisations. ASCS also has a library with a number of CP publications, which anyone can borrow. Information is also available on our website.

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Copies of this booklet can be made available in a range of alternative formats. Please contact ASCS for details

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