



# **GETTING TO KNOW CEREBRAL PALSY**

**A learning resource for facilitators, parents, caregivers,  
and persons with cerebral palsy**



## **Module 1 Introduction**

## Cerebral Palsy Association (Eastern Cape)

The Cerebral Palsy Association (Eastern Cape) was established in Port Elizabeth, in 1955. The primary mission of the Association is to encourage, assist and care for all persons affected by cerebral palsy, and assist them to attain their maximum potential and independently integrate into the community. The Association is a registered Non-Profit Organisation, and is affiliated to the National Association for Persons with Cerebral Palsy in South Africa.

The Association presently operates from its own premises in Port Elizabeth. It has a permanent staff of three part-time and five full-time employees, ably assisted by a network of volunteers. The Association is directed by an Executive Management Committee of 12 members, who are elected bi-annually and serve on a voluntary basis.

### Funders

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# About Hambisela

Parents and caregivers are in the front-line of caring for individuals affected by cerebral palsy and assisting with their treatment. Historically, individuals in rural and under-developed areas had no or limited access to skills and training to assist them with skills development. This very often compromised the level of primary care and therapy that individuals affected by cerebral palsy could obtain in these areas.

To address this problem and improve the level of daily care available to individuals affected by cerebral palsy, especially in rural and under-developed areas, the Cerebral Palsy Association (Eastern Cape) identified a need to transfer skills to parents and caregivers through the following measures:

- Develop training programmes in basic skills for parents and primary caregivers of individuals affected by cerebral palsy;
- Present these training courses to parents and primary caregivers;
- Facilitate specialized therapy training for nurses and sisters from community clinics;
- Develop the pool of specialized therapy skills in the Eastern Cape, especially in rural areas;
- Offer supplementary therapy to individuals from schools in the Eastern Cape, to supplement the reduction in therapy support from schools.

In 2005 the Cerebral Palsy Association initiated the Hambisela project as Center of Excellence in Therapy for Cerebral Palsy, to develop and promote excellence in therapy for cerebral palsy through community-based programmes.

Hambisela is based at the Association's premises in Port Elizabeth. Hambisela has developed a series of 7 training modules in the "Getting to know Cerebral Palsy" series, each comprising a Facilitator Manual, an Activity Pack, course display material, and a Trainee Handout. Hambisela is using this series as a primary resource to develop the skills of parents and caregivers of children with cerebral palsy in the community.

## **Getting to know Cerebral Palsy: List of Modules:**

Module 1: Introduction

Module 2: Evaluating Your child

Module 3: Positioning Your child

Module 4: Communication

Module 5: Everyday Activities

Module 6: Feeding Your child

Module 7: Play

# **MODULE 1**

## **INTRODUCTION**

### **PLANNED OUTCOMES**

**When you have finished this workshop, you should have a clearer understanding about cerebral palsy, and be able to explain to someone else:**

- 1. What cerebral palsy is.**
- 2. The causes of cerebral palsy.**
- 3. What cerebral palsy looks like.**
- 4. How the brain influences movement and posture.**
- 5. Other problems often found with cerebral palsy.**

# Introduction

## 1. WHAT IS CEREBRAL PALSY?

- *Has anyone ever told you why your child is not developing as expected, or why your child is disabled?*
- *What has the doctor or nurse told you?*
- *What do your family or neighbours say about your child?*
- *Have you ever heard the words CEREBRAL PALSY?*

**Cerebral palsy is damage to part of the brain causing problems with movement and/or posture.**

### **Medical definition:**

Cerebral palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviours, by epilepsy, and by secondary musculoskeletal problems. (Rosenbaum et al., 2007)

Think about the following questions one by one, and see what your answers are. Discuss the questions and answers in your family.

**Question:** *Can other children catch cerebral palsy? Is it contagious?*

NO. It cannot be passed from one child to another.



**Question:** *Are all children with cerebral palsy the same?*

NO. Cerebral palsy affects each child differently. Each child is unique, just as you are different from your neighbour, and your sister, mother, uncle, twin...



**Question:** *Will my child die from cerebral palsy?*

Cerebral palsy normally does not affect life-expectancy. Your child with cerebral palsy will grow up to be an adult with cerebral palsy. However, some of the complications of cerebral palsy (for example, severe postural problems leading to decreased lung capacity) can be life threatening.



**Question:** *Can children with cerebral palsy go to school?*



All children have the right to education. Generally speaking, in South Africa parents and teachers have low expectations of children with cerebral palsy. What do you expect of your child? Remember, all children have the right to education, and that includes children with cerebral palsy.

**Question:** *From what backgrounds do children with cerebral palsy come? Do they live in cities, or on farms? Are they rich or poor?*



From all backgrounds. There are children (and adults) with cerebral palsy in every country of the world. And from every city, or town, or rural area. There are poor communities with children with cerebral palsy, and rich communities with children with cerebral palsy. It is commonly accepted that about one in every 400 children all over the world has cerebral palsy. There are no known published statistics about the incidence of cerebral palsy in South Africa.

**Question:** *Do children with cerebral palsy always have below average intelligence?*



Many children with cerebral palsy have average or above average intelligence. Some children with cerebral palsy have below average intelligence, and some may be profoundly intellectually disabled. But many children with cerebral palsy are labeled with an intellectual disability too early, especially when they have difficulty communicating, and are then not helped or trained to their fullest potential.

**Question:** *Can cerebral palsy be cured?*



Cerebral palsy cannot be cured. Early help and training can help children's development. Remember your child with cerebral palsy will develop into an adult with cerebral palsy. Searching for a cure will only bring disappointment. Rather help your child to become an adult who can live with her disability and be as independent as possible. Sometimes, when a child is older and her muscles have become very stiff over a long time, operations can be done, or very strong medication can be used, which can help the child to sit or lie more comfortably.

**Question:** *Does cerebral palsy get worse?*



No. The damaged parts of the brain do not get better, but neither do they get worse. The child's movements, body positions and the other problems we spoke about can become more obvious as the child gets older, and seem worse, but they can also be improved. It depends on the amount of damage, and on how we handle and position the baby/child. The earlier you start to help your child to learn, the more she can develop.

Sometimes, illnesses that affect the brain, like meningitis, or very severe prolonged bouts of epilepsy, can cause further damage to the child's brain. Such a child's disability will probably then become worse.

## 2. WHAT CAUSES CEREBRAL PALSY?

Now that we have discussed what cerebral palsy is, let's look at what the causes of cerebral palsy are.

- *What do you think causes cerebral palsy?*
- *What do you know about the causes?*
- *What have you heard?*
- *What do you believe?*

The following posters show all the risk factors that are associated with cerebral palsy – either before, during or after birth.

<b>Risk factors before birth</b>	<b>Risk factors around the time of birth</b>	<b>Risk factors after birth</b>
<ul style="list-style-type: none"> <li>• Unknown cause</li> <li>• Alcohol and other drugs</li> <li>• Infections and illnesses of the mother while she is pregnant</li> <li>• Rhesus incompatibility</li> <li>• Sexually transmitted diseases</li> <li>• Attempted abortion</li> <li>• Teenage pregnancy</li> <li>• Pregnancy at an advanced age</li> </ul>	<ul style="list-style-type: none"> <li>• Unknown cause</li> <li>• Lack of oxygen</li> <li>• Birth injuries</li> <li>• Baby born too early</li> <li>• Jaundice (yellow baby)</li> </ul>	<ul style="list-style-type: none"> <li>• Very high fever</li> <li>• Brain infections</li> <li>• Head injuries</li> <li>• Lack of oxygen</li> <li>• Poisoning</li> <li>• Near drowning</li> </ul>

Below is a more detailed list for you to refer to, and to help you answer any questions.

### ***Risk factors before birth:***

#### **Unknown cause**

No cause can be found in about 30% of children.

#### **Alcohol and other Drugs**

Drugs are not good, as they disturb the brain. Drugs are substances such as alcohol, tobacco, cocaine, glue, and non-prescription medication. If a pregnant mother uses drugs, they move through the blood to the umbilical cord and, from there, to the child which may cause damage to the child's brain that is still developing, e.g. a drunken person doesn't walk properly and his mind does not function well. In the same way, any drugs the mother takes will affect the child.

#### **Infections of the mother while she is pregnant**

These include German measles and shingles (herpes zoster). If a mother has German measles, her child can become disabled even before birth. This is why it is very important to immunise girls against this disease when they are twelve years old.



### **Illnesses of the mother**

Diabetes

Toxaemia of pregnancy

High blood pressure

If the mother has high blood pressure, her blood vessels become hardened or narrower.

The blood circulation decreases, and the child won't receive enough blood and oxygen.

### **Rhesus incompatibility**

When the blood of the mother and child doesn't go together well, there may be blockage. This may result in the clotting of brain vessels.

### **Sexually transmitted diseases**

HIV / Aids - If a pregnant mother is HIV positive, there is a greater chance of her giving birth to a child with cerebral palsy than when the mother is HIV negative. The risk of cerebral palsy is also higher because the mother may already be immune-compromised or malnourished.

Neurosyphilis - This disease is curable but, if left untreated, it may cause a child to become disabled or blind.

### **Attempted abortion**

If there was an attempted abortion, the child's brain may be affected.

### **Teenage pregnancy**

When a mother is not yet physically ready to have a child, the unborn baby may sustain brain damage through prolonged delivery, due to the pelvis being too narrow. (A father under the age of 20 is a risk factor too, though not due to the size of his pelvis!)

### **Becoming pregnant at an advanced age**

If a mother falls pregnant when she is over 40 years old, especially if it is her first child, her child may have cerebral palsy. When the mother is already older, her pelvic bones are hardened, as they haven't opened before. Delivery can be expected to be more difficult.

## **Risk factors around the time of birth:**

### **Lack of oxygen (air) at birth**

The baby does not breathe soon enough and becomes blue and limp. In some areas, mis use of hormones (oxytocics) to speed up birth narrows the blood vessels in the womb so much that the baby does not get enough oxygen. The baby is born blue and limp-with brain damage.

### **Birth injuries from difficult births**

These are mostly large babies of mothers who are small or very young. The baby's head may be pushed out of shape, blood vessels torn, and the brain disturbed.

### **Baby born too early (pre-maturity)**

Babies born before 9 months and who weigh less than 2 kilos (5 pounds) are much more likely to have cerebral palsy. In rich countries, over half the cases of cerebral palsy happen in babies that are born early.

### **Jaundice (yellow baby)**

Developing jaundice, which is a sign of an immature liver, may affect the central nervous system.

## **Risk factor after birth:**

### **High fever and dehydration**

Very high fever due to infection or dehydration (water loss from diarrhoea). It is more common in bottle-fed babies.

### **Brain infections**

From meningitis or encephalitis. There can be many causes, including malaria and tuberculosis.

### **Head injuries**

This can be from accidents, falling, and baby battering.

### **Lack of oxygen**

From near drowning, gas poisoning, severe pneumonia or TB, or other causes.

### **Poisoning**

From lead glazes on pottery, pesticides sprayed on crops, and other poisons.

### **Bleeding or blood clots in the brain**

Often from unknown cause.

### **Brain tumours**

A tumour is tissue in the brain that grows without control, causing pressure and damage to the brain. The signs are similar to cerebral palsy but steadily get worse ie it is progressive.

### 3. WHAT DOES CEREBRAL PALSY LOOK LIKE?

These are pictures of children with cerebral palsy. As you can see they may sit, lie or stand differently to able bodied children.

**Question:** *Can you see any pictures that remind you of how your child may look?  
Or maybe you have seen another child who looks similar?*







As you will see in the pictures, no two children look exactly the same. It is important to remember that cerebral palsy affects every child differently. However, there are some broad categories which describe the main ways in which a child can be affected.

Let's look at these different ways that cerebral palsy can appear.

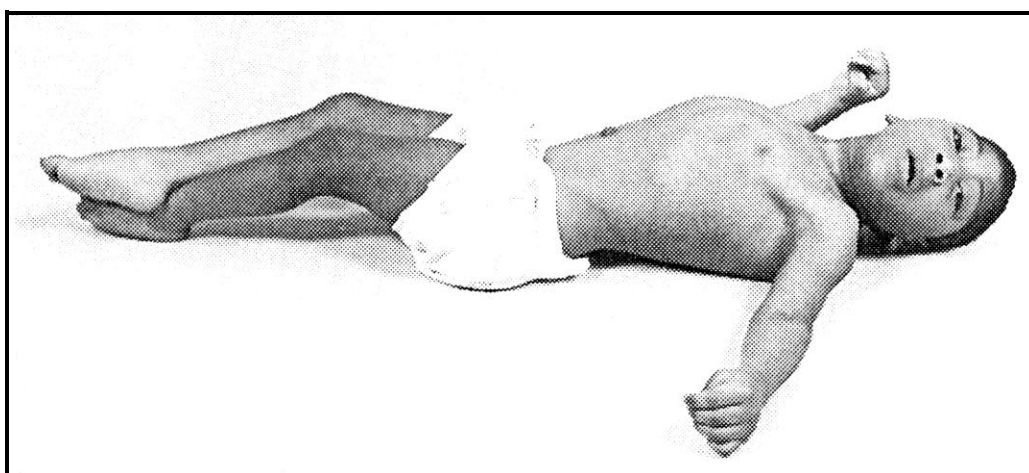
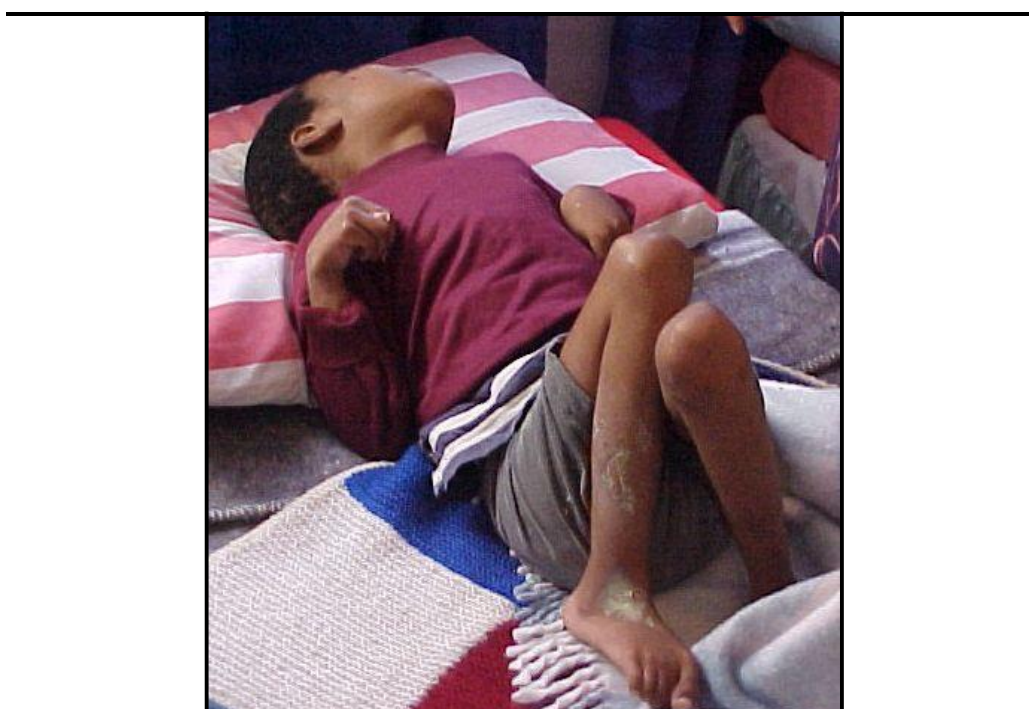
We'll start with the child whose muscles are stiff. Medical people will call this „spasticity“ or „hypertonia“.

### 3.1 Muscle Stiffness or 'Hypertonia'

The child who has **muscle stiffness**, or 'muscle tension'. This causes part of her body to be rigid, or stiff. Movements are slow and awkward. Often the position of the head triggers strange positions of the whole body. The stiffness increases when the child is upset or excited, or when her body is in certain positions. **The pattern of stiffness varies greatly from child to child and she has no control over these movements.**

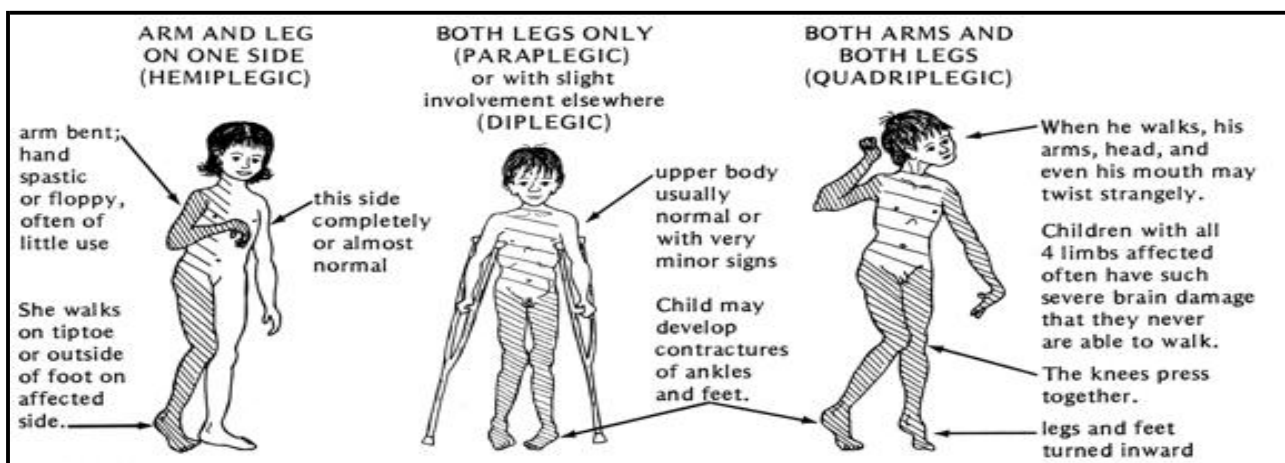
These are children with stiff muscles.  
Notice the positions that the stiff parts of the body go into.

**Question:** *Are any of these positions typical of the positions of your child's body?*





Hypertonia“ is the most common way that individuals are affected by cerebral palsy, and it is divided even further according to which parts of the body are mainly affected.

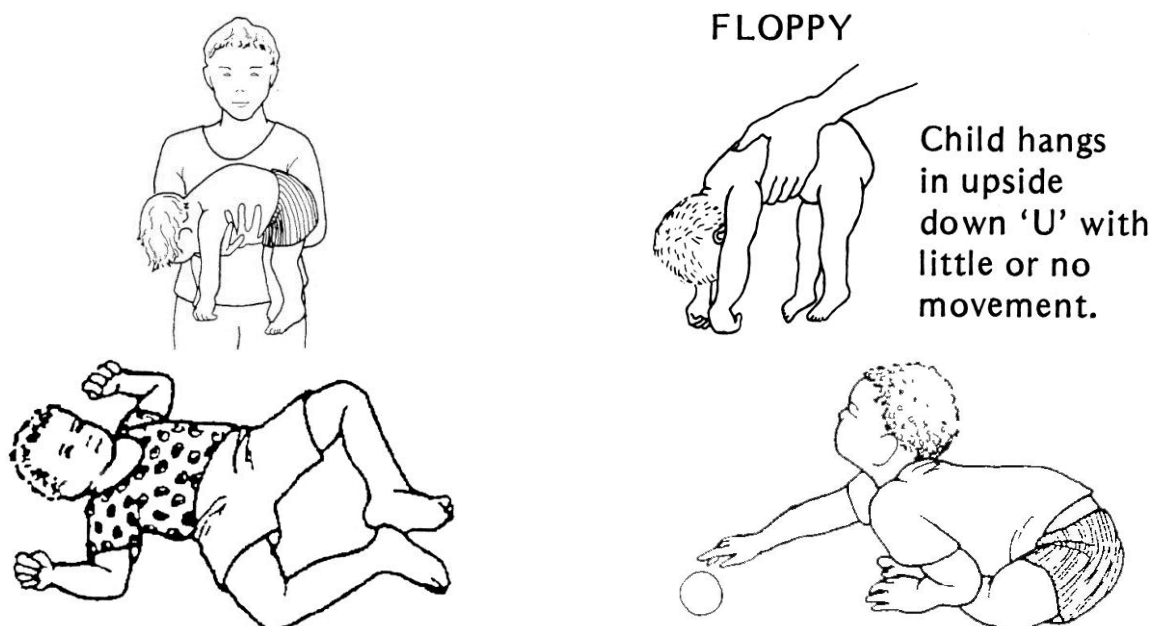


The terms the medical people use here are: hemiplegia, diplegia, and quadriplegia.

## 3.2 Floppy muscles or 'Hypotonia'

Another type of cerebral palsy is when the child's muscles are very floppy. This is called „hypotonia“.

Children who have very floppy muscles often look like the children in these pictures. The floppiness of the muscles can make it difficult for the child to move easily, and she may get tired quickly, for example when trying to sit by herself. When she lies on her back, her legs will often flop outwards.



Here's another way a person may be affected: instead of stiff or floppy muscles, they may have uncontrolled muscles movements. Medical people will use the word „athetosis“.

## 3.3 Uncontrolled Movements or 'Athetosis'

- These children move too much. They have difficulty staying still and stable. They cannot control these movements.
- There can be different types of uncontrolled movements seen in different children:
  - It can be slow, wriggly, or sudden big movements of the child's feet, arms, hands, or face muscles.
  - Stiff movements or positions like those shown in the section of muscle stiffness may continually come and go.
- When the child tries to move, her body parts move too fast and too far.
- Her balance is poor and she falls over easily.



- Many children with athetosis have normal intelligence, but if the muscles needed for speech are affected, it may be hard for them to communicate their thoughts and needs.
- Uncontrolled movements are often worse when the child is excited or tries to do something.

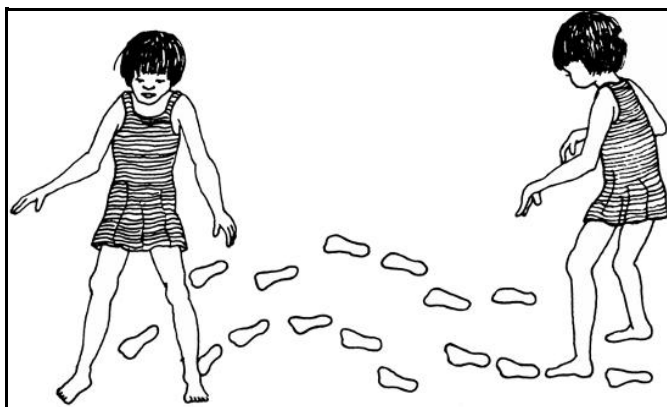
The next 2 pictures show children with this kind of moving difficulty:



AND now for the final way in which a person may be affected, where the child with cerebral palsy has poor balance. This kind is not so common, and it is called „ataxia“.

### 3.4 Poor Balance or 'Ataxia'

The child who has 'ataxia', or poor balance, has difficulty beginning to sit and stand. She falls often, and has very clumsy use of her hands. All this is normal in small children, but in the child with ataxia it is a bigger problem and lasts longer (sometimes for life). If you put your hand on this child's head, you may feel a constant „shake“ under your hand.



To keep her balance the child with ataxia walks bent forward with feet wide apart. She takes irregular steps, like someone who is drunk.

Now that we have learned about the different types of cerebral palsy, it is also important to note that many children may have more than one type at the same time. For example, a child could have floppy muscles, and uncontrolled movements, in different parts of her body.

Children with any type of cerebral palsy **are often mainly limp or floppy as babies**. Stiffness or uncontrolled movements begin little by little. Or the child may be limp in some positions and stiff in others.

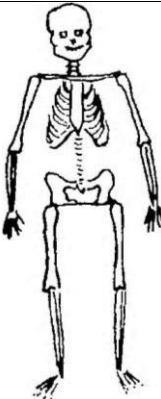
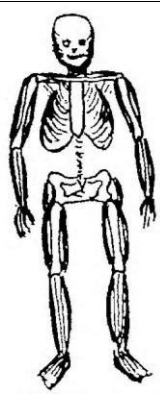
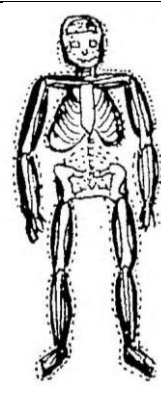
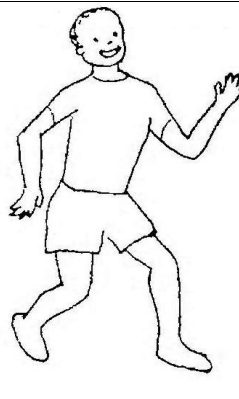
## 4. HOW DOES THE BRAIN INFLUENCE MOVEMENT AND POSTURE?

Look again at the definition of cerebral palsy:

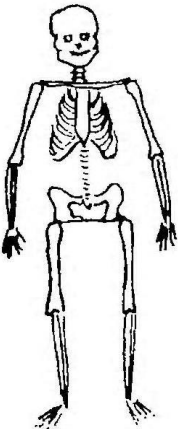
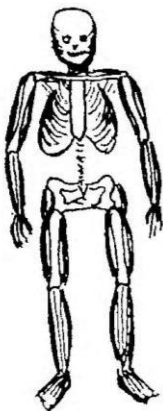
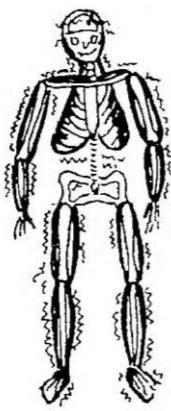

**Cerebral palsy is damage to part of the brain which causes problems with movement and/or posture.**

Look especially at the words “brain” and “damage” and “movements”.

The following pictures show how the brain helps, or, with cerebral palsy, doesn’t help, a person’s muscle movements.

			
<p>Inside our bodies we have a framework of bones – the skeleton.</p>	<p>Attached to all the bones are muscles, which contract and relax to make the body move.</p>	<p>But these muscles cannot work alone. They need orders. These orders, or messages, are sent from the muscle centre of the brain via pathways which we call the nerves.</p>	<p>So when a person decides to make a movement, the brain registers this. The muscle centre then sends a message to the muscles telling them what movements to make.</p>

Now let’s look at what happens to a person with cerebral palsy...

			
<p>Inside our bodies we have a framework of bones – the skeleton. The bones are not damaged, so there’s no problem here.</p>	<p>Attached to all the bones are muscles, which contract and relax to make the body move. The muscles are not damaged, so there’s no problem here either.</p>	<p>But when a child has cerebral palsy, the muscle centre of the brain is disturbed and does not send the right messages along the nerves.</p>	<p>So, when a person decides to make a movement, the brain registers this, but the muscle centre sends a disordered, uncontrolled message, so the person is unable to make the movements he wants to. This can affect some or all of the muscles of the body.</p>

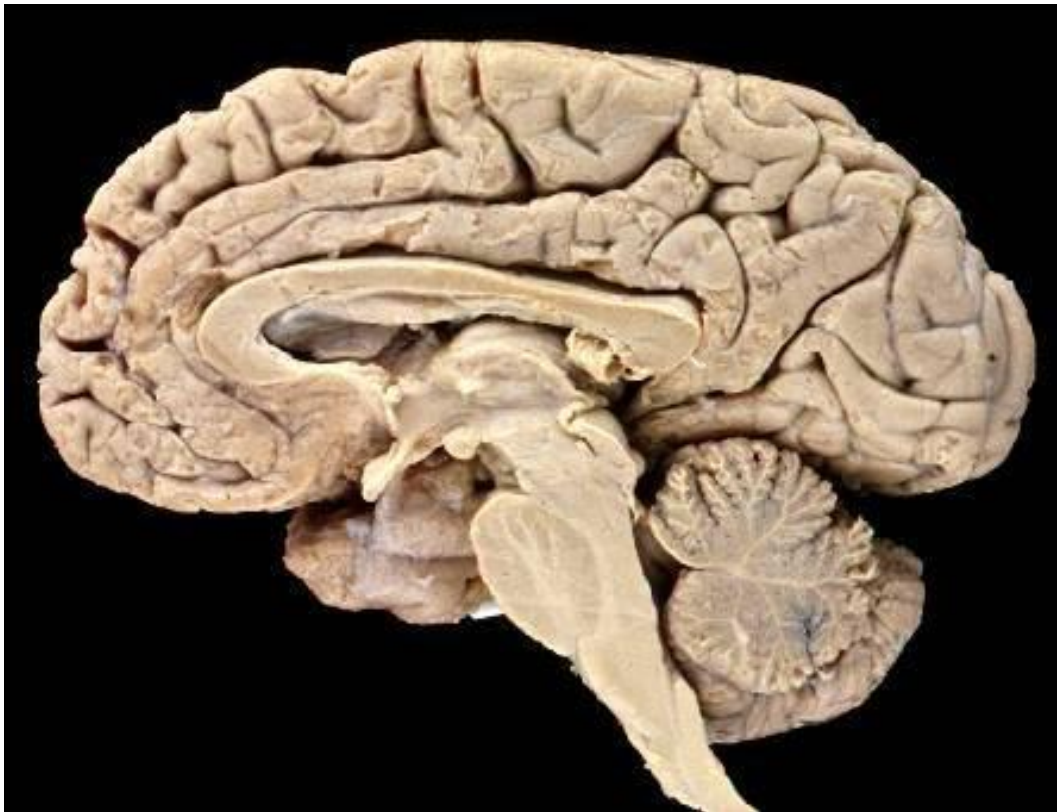
**Question:** *Apart from controlling the movements of the body, can you think of other functions/jobs the brain has? What else do we use our brains for?*



Our brain controls everything that our body does: not only controlling our muscles that allow us to move; but also controlling things that we cannot see physically, such as our memories and thinking.

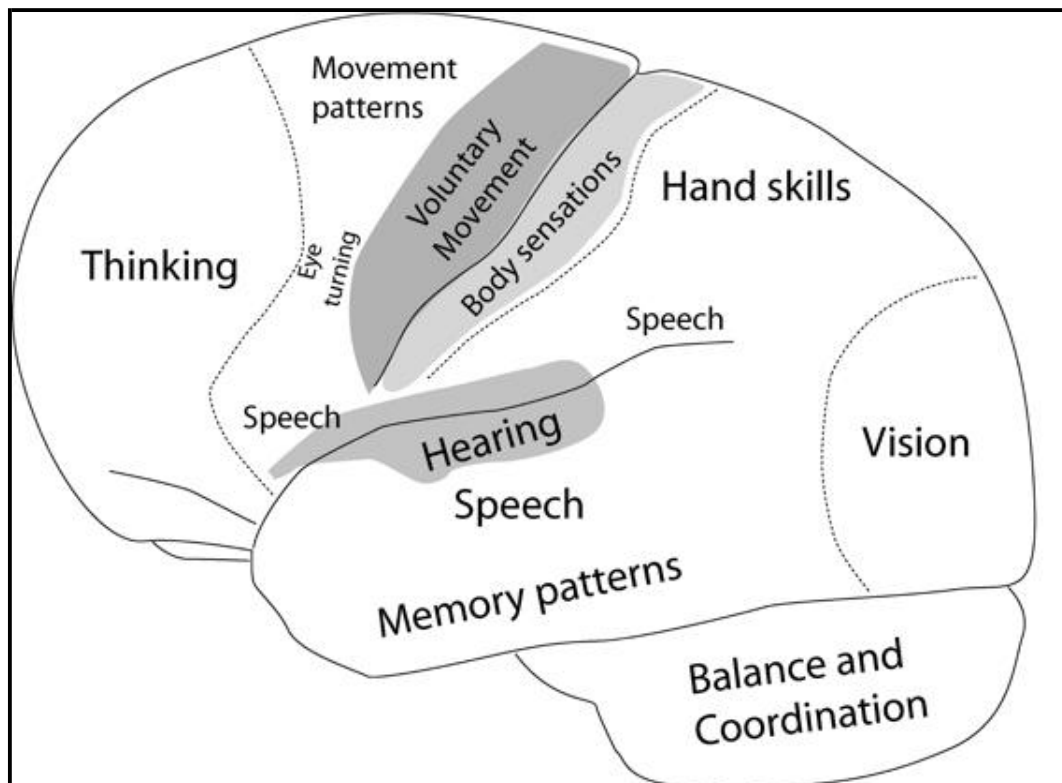
Our brains do many things, and have many parts to them. All parts are connected to the others, and work together.

This is a photograph of an actual brain.



Each part has a specific function.

This is a diagram to represent the brain and some of its functions.



As you can see, there are different areas of the brain that control the different things. Remember, cerebral palsy occurs when there is damage to **PARTS** of the brain. It is not the whole brain that is damaged. That means that there are other parts of the brain that are not damaged and that are working well.

The damaged parts of the brain do not get better, but also do not get worse. The child's movements, body positions and the other problems can become more obvious as the child gets older, and seem worse, but they can also be improved – depending on the amount of damage, and how we handle and position the baby/child.

The earlier you start to help your child to learn, the more she can develop.

## 5. WHAT OTHER PROBLEMS ARE OFTEN FOUND WITH CEREBRAL PALSY?

We have learned that „cerebral palsy“ is damage to part of the brain that controls movement and posture. We have also learned that different parts of our brain control different functions. So children with cerebral palsy may have other problems apart from difficulty with body movements.

**QUESTION:** *What other difficulties or problems might children with cerebral palsy have? Think of your own child, and what she struggles with.*



Think about your experience with your child.

- **Difficulty learning to chew and swallow, and talk**
- **Difficulty communicating**
- **Epilepsy ('fits')**
- **Poor eyesight/squint**
- **Hearing difficulties**
- **Perception difficulties**
- **Slow to learn**
- **Challenging behaviour**
- **Growth problems**
- **Dental problems**
- **Constipation**
- **Sleep problems**

Remember that children may have one, a few, many, or none of these associated conditions. Some conditions may be directly from the brain damage, and some come as a result of slow development, frustration etc.

The descriptions below give you more information. Some of these associated conditions will be covered in depth in later modules.

### **Difficulty learning to chew and swallow, and talk**

Eating and speaking both depend on the ability to control the muscles of the tongue, lips and throat. When muscle control is poor, there may be difficulties with learning to chew and swallow. Learning to speak can be delayed. Helping a child to eat more normally is an important preparation for learning to speak. Try to feed her some solid food so she can learn to chew.

With encouragement and opportunity, many children with cerebral palsy learn to speak, although the words may not be clear enough for other people to understand.

### **Difficulty communicating**

The child's words may not be clear enough for you or other people to understand. In this case, the child's needs would have to be expressed in other ways, such as pointing, with her hand, or foot, or eyes; or using gestures.... It is vital that some way is found for communication.

### **Epilepsy**

Some children with cerebral palsy may develop epilepsy (fits, seizures, convulsions). Medication is often used to control this.

### **Poor eyesight/squint**

Many young babies do squint from time to time, but this stops as they get older. Children older than six months with a squint should be taken to an eye doctor because neglecting it can mean that the child only uses one eye. A few children may need an operation. Others will be helped by wearing glasses prescribed by an eye doctor. Later, a specific eye problem can lead to a learning difficulty. Get your child checked to see if this may be a problem.

### **Hearing difficulties**

Some children, especially those with athetoid cerebral palsy, may have difficulty hearing. This makes learning to speak more difficult. If you think she has a hearing problem, consult a doctor. Some children can be helped with a hearing aid. Remember, communication is vital.

### **Perception difficulties**

This is a problem with the brain not being able to make sense of what the child sees or hears or touches, and not necessarily with her eyesight or hearing. The child may be overly sensitive or she may be less sensitive than usual to sensory information like sounds or touch.

### **Slow to learn**

About half the children with cerebral palsy are slow to learn (intellectual disability). They cannot learn many school-type skills, or basic skills to look after themselves. Others, especially those with athetoid cerebral palsy, have average or good intelligence. Children who cannot talk clearly or control the muscles of their face very well are often thought to be mentally slow. This is not always so. The part of the brain that controls talking and muscles is different to the part that allows you to understand and think.

### **Challenging behaviour**

Some children have special difficulty learning acceptable and appropriate behaviour. Many children with cerebral palsy also have an intellectual disability. This means they cannot reason well or understand their environment fully. Challenging behaviour most frequently happens within this group, and especially where someone cannot communicate effectively (causing frustration and anger). However, some children without intellectual disability also have challenging behaviour (like attention seeking).

### **Growth problems**

Babies with eating difficulties may be slow to gain weight. Older children may be thinner than usual because they move about less and their muscles do not develop. This can be clearly seen in children with hemiplegia, where the affected arm and leg are usually thinner and shorter than the other arm and leg. Other children on the other hand, may be fed too much, and gain too much weight, which makes many activities and handling more difficult.



### **Dental problems**

Some medications may increase the risk of gum disease. Dental problems often occur in children who have difficulty controlling how they open their mouth, have a bite reflex, or have poor control of their tongue muscles to remove food pieces between the teeth and are reliant on others to clean their teeth for them.

### **Constipation**

This is very common in people with cerebral palsy, especially in those who move less. A poor diet related to poor eating and swallowing and inadequate fluid intake are the main reasons.

### **Sleep problems**

Lots of children have difficulty sleeping. But in children with cerebral palsy, there may also be physical causes, such as discomfort, or having to be turned regularly, or breathing difficulties. Some medications may interfere with sleep.

**Remember: ask someone you trust, if you have any new worries or concerns about your child, or if something needs to be done. For example, children who have fits should usually be on regular medication.**

## **6. WHAT IS CEREBRAL PALSY? EXPLAIN IT IN YOUR OWN WORDS**

We are coming to the end of this module. We have looked at:

- 1. What cerebral palsy is**
- 2. The causes of cerebral palsy**
- 3. What cerebral palsy looks like**
- 4. How the brain influences movement and posture**
- 5. Other problems often found with cerebral palsy**

It is very important that you understand this information yourself. But it is just as important that you share the information you have learned with the other members of your household, and within your community. You will probably need to practice sharing this information so that you feel comfortable doing it.

# Sources and References

Ideas from many sources have helped us to develop the Hambisela programme. The following material and references have been particularly helpful, either as sources or as inspiration on how to present training, and we gratefully acknowledge their use.

In many cases we have been given permission to use photographs. Where permission could not be obtained, the faces have been re-touched in order to protect identity.

1. "Disabled Village Children – A guide for community health workers, rehabilitation workers, and families", David Werner, The Hesperian Foundation, Berkeley (1999).
2. "Promoting the Development of Young Children with Cerebral Palsy – A guide for mid-level rehabilitation workers", World Health Organisation, Geneva (1993).
3. "Let's Communicate – A handbook for people working with children with communication difficulties", World Health Organisation, Geneva (1997).
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