

# What to Know About Cerebral Palsy



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## What's in this Book

What Is Cerebral Palsy (CP) .....	1
What Causes CP? .....	4
The Effects of CP .....	5
The Main Forms of CP .....	7
Management of CP Is Important!.....	8
Other Methods for Managing CP .....	9
Helpful Programs for Children with CP .....	11
Q and A about CP .....	12

This booklet is not a substitute for an informed discussion between a patient and his or her health-care provider of the procedures or medications described in this booklet.

## What is Cerebral Palsy (CP)?

CP is a group of brain disorders that affects movement. It results from damage to the brain that happens before or during birth, or in the first year of life.

### CP Affects Muscle Tone and Coordination

In a person with CP, the brain cannot send proper signals to the muscles. The person is unable to control how certain muscles tighten or relax.

- CP is **not** a disease.
- The brain damage does not get better or worse, but a person's condition can change as they develop.
- CP is **not** contagious (it can't be passed from one person to another).

### CP Can Be Mild or Severe

- Mild cases may have only a minor effect on coordination.
- More severe cases may affect mobility, daily living skills and speech.

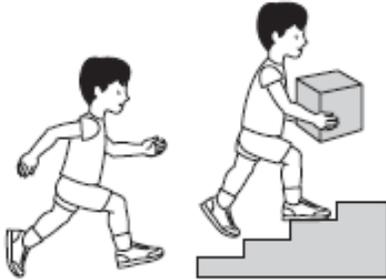
The degree of severity depends on where and how the brain is damaged.

The chart on the next page shows how doctors figure out the degree of your child's CP.

### **There is Good News!**

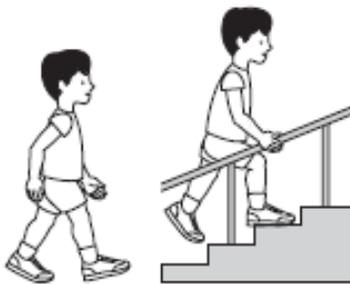
While CP cannot be cured, brain function can improve. The earlier treatment is started, the better!

## GMFCS E & R between 6<sup>th</sup> and 12<sup>th</sup> birthday: Descriptors and illustrations



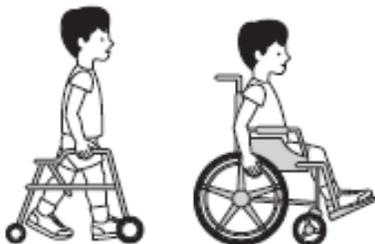
### GMFCS Level I

Children will walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and co-ordination are limited.



### GMFCS Level II

Children walk in most settings and climb stairs using a railing. They may experience difficulty walking long distances, and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a hand-held mobility device or use wheeled mobility over long distances. Children only have minimal ability to perform gross motor skills such as running and jumping.



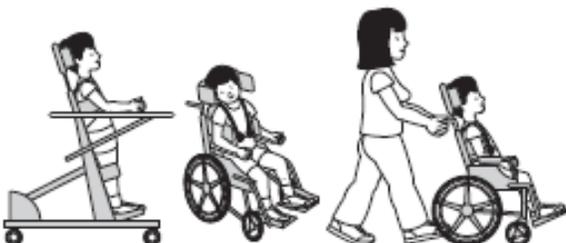
### GMFCS Level III

Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a rail with supervision or assistance. Children use wheeled mobility devices when traveling long distances and may self-propel for shorter distances.



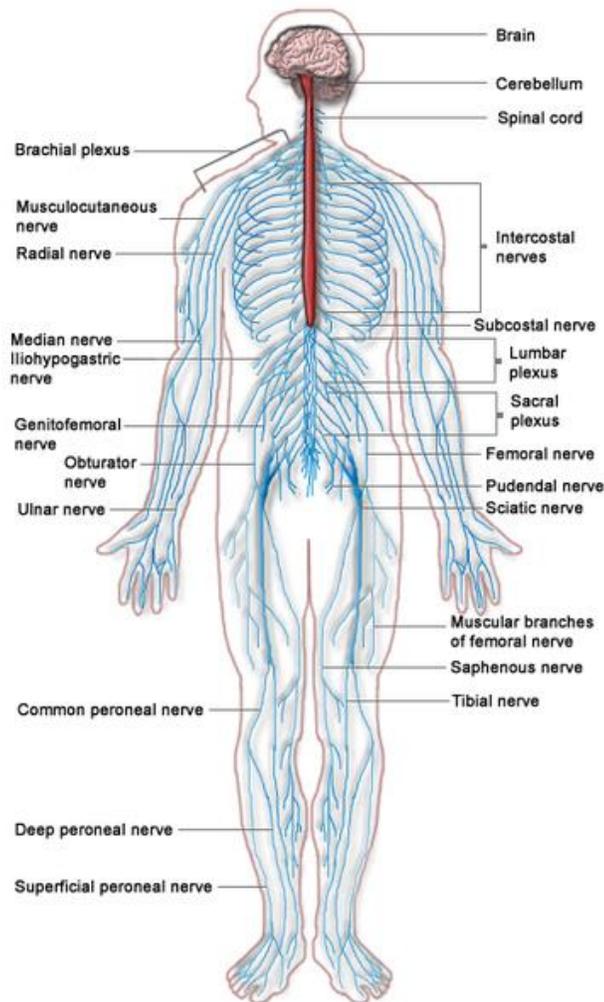
### GMFCS Level IV

Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors, and in the community children are transported in a manual wheelchair or use powered mobility.



### GMFCS Level V

Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.



The brain tells the nerves what messages to send.

The nerves tell the muscles what to do.

Then the muscles tell the bones how to grow.

## People with CP Face Many Challenges

CP can affect a person's:

- **Body**— CP can make it harder to walk, talk, use the hands and develop other physical skills.
- **Mind**— Sometimes, the brain injury that causes CP also affects the person's ability to learn.
- **Relationships with others**— A person with CP may have trouble interacting with others.

Learn how people with CP can meet these challenges.

## What Causes CP?

There are many possible causes.

### **Most Cases Happen Before or During Birth**

For example, CP may be caused by:

- premature (born early) delivery
- low birth weight
- not enough oxygen to the baby's brain during labor or delivery
- a stroke (not enough blood flow to part of the brain) in the unborn baby
- Rubella (measles) or other infections in the mother during pregnancy.
- a condition that is passed down from family members that affects the development of the brain.
- use of alcohol or other drugs by the mother

### **Some Cases Occur After Birth**

Reasons may include:

- severe jaundice
- brain infections
- head injuries – mainly from car crashes, falls or child abuse
- lead poisoning

## The Effects of CP

### Signs Can Be Different From Person to Person

CP symptoms appear early in life. They may not be clear at first, but a parent or health-care provider may notice signs like:

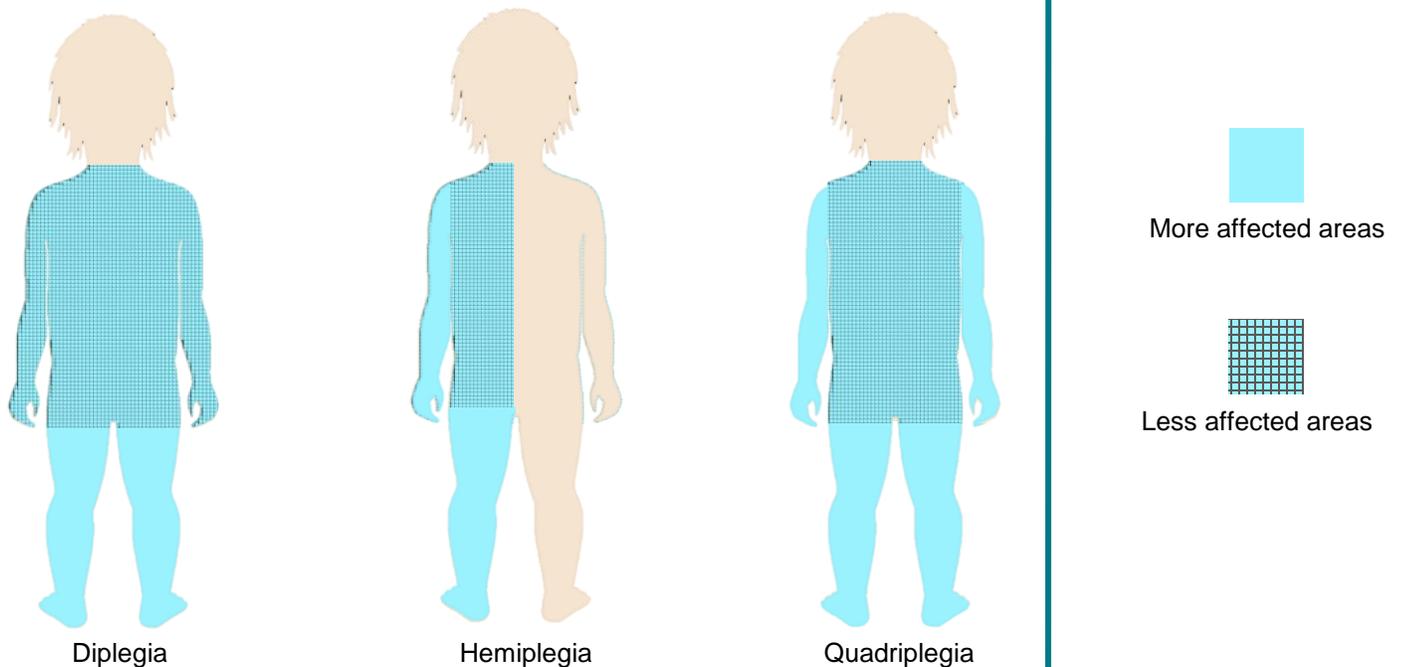
- very stiff muscles
- very relaxed muscles
- trouble feeding, sucking or swallowing
- trouble moving arms or legs
- delay in reaching milestones such as sitting up or crawling
- trouble speaking

### CP Can Affect Different Parts of the Body

For example, it may affect:

- one or both legs
- one side of the body
- the whole body

Management of CP depends on which parts of the body are affected.



## Other Conditions Often Appear With CP

People with CP may also have:

- seizures
- communication problems
- hearing difficulties
- learning difficulties
- difficulties seeing

They may also develop:

- joint problems or “contracture” (shortening of muscles and other tissues)
- respiratory problems
- dental problems

## If CP Is Suspected

**There is no single test for cerebral palsy. It may take months to reach a clear diagnosis. Your child does not have to have a final diagnosis of CP to start getting some services.**

## Diagnosis Usually Involves Several Steps

- evaluating the child’s motor skills (the ability to sit, roll, etc.)
- reviewing the child’s and mother’s medical histories
- testing reflexes
- ruling out other possible causes of symptoms

## Other Tests May Explore Causes and Effects of CP

- Magnetic resonance imaging (MRI) or computed tomography (CT) scans may reveal brain abnormalities.
- Hearing, vision and intelligence testing may identify complications that may come with CP.
- Blood tests may find related medical problems

**Patience is important. It can take time to understand everything about a child’s condition.**

## The Main Forms of CP

There are several different kinds of CP that your child may have:

- **Spastic**

This is the most common type of CP. In spastic CP, the person's muscles remain tightened and seem stiff. Movements that a person chooses to do (voluntary movements), like walking, are more difficult.

- **Athetoid or Dystonic**

With this type of CP, a person has involuntary movement of the face, hands and other parts of the body. (Involuntary movements are things the body does on its own, that a person may not be able to control.)

- **Ataxic**

This form of CP causes balance and coordination problems. Walking may be unsteady.

- **Hypotonic**

In hypotonic CP, the person has very relaxed muscles causing problems with posture and movement.

- **Mixed**

This is a combination of CP types. For example, one combination is spastic and dystonic forms.

### CP Affects Different Parts of the Brain

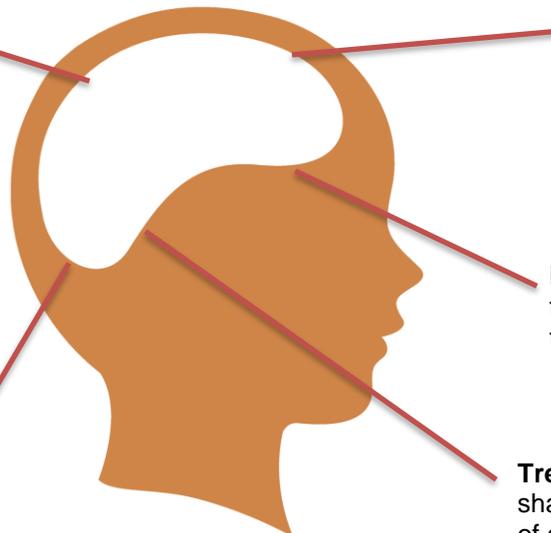
**Spastic**— tense, contracted muscles (most common type of CP)

**Athetoid**— constant, uncontrollable movement of arms, legs, head, and eyes

**Ataxic**— poor sense of balance, often causing falls and stumbles

**Rigidity**— tight muscles that resist effort to make them move

**Tremor**— uncontrollable shaking getting in the way of coordination



## Management of CP Is Important!

Unlike multiple sclerosis or muscular dystrophy, CP is “non-progressive.” This means the brain damage that caused CP will **not** get worse.

But, CP symptoms can get better or worse over time. Proper management – and family involvement – are keys to a brighter future.

## Therapy for CP

Therapy may involve different health-care specialists, approaches and equipment.



- **Physical Therapy (PT)**  
PT can improve muscle flexibility and movement. It can also help the person with CP master movements such as sitting, crawling and walking.
- **Occupational Therapy (OT)**  
OT helps the person with CP have skills needed for everyday activities, like eating and dressing. It focuses on fine motor skills and use of the senses.
- **Speech and Language Therapy (SLP)**  
Speech therapy helps improve communication skills. This may include speech, or sign language and other communication methods. Speech and language therapy can also help with drooling or eating difficulties.

### The Sooner Therapy Begins, the Better

You can help your child manage CP better if treatment begins early. It helps prevent many complications and helps lead to greater independence.

## Other Methods for Managing CP

### Braces (Orthotic Devices)

Many people with CP use braces. Braces may help with movement and development and help prevent contractures.

### Medicine

We can sometimes use medicine to treat conditions related to CP. For example, medicine can help control seizures. Medicine may also help control muscle spasms and other symptoms.

### Surgery

In some cases, a surgeon may repair complications such as contractures or joint dislocations. Surgery to cut certain nerves or muscles may help make arms and legs less spastic.

It may be very helpful to talk about the risks and benefits of all treatments with a health-care provider.

## Special Equipment Can Help

Special kinds of equipment can help people with CP develop to their fullest. We sometimes call special equipment “assistive technology.” It can help improve communication, movement, and daily living.

### Communication

A person with CP may benefit from these kinds of things:

- Special computers that don't use keyboards
- Recorders for taking notes
- Calculators for developing math skills
- Communication apps for iPads or tablets
- Simple things like bigger pencil grips and large-print workbooks can also make a big difference.



**Assistive technology can help build independence and self-confidence.**

### **Moving Around**

A person with CP may need help in moving around more effectively. Here are some things that can help.

- Power or manual wheelchairs
- Walkers and crutches
- Ramps
- Lifts
- Bars and railings

### **Daily Living**

People with CP often benefit from changes in the home.

- Ramps
- Bath seats
- Forks, knives and spoons, modified for better gripping
- Lever door handles
- Lowered appliances

### **You May Be Able to Get Help to Pay for Assistive Technology**

Federal, state and local governments may have funding. Insurance may also provide some coverage. Contact the National Information Center for Children and Youth with Disabilities (NICHCY) for more information

## Helpful Programs for Children with CP

### Early Intervention Programs (EIPs) for Children 0-2

EIPs can identify and begin treating a child's disabilities as early as possible.

Every child in an EIP gets an Individualized Family Service Plan (IFSP). The IFSP gives specific information about goals for the child and services available to the family.

### Preschool Special Education Programs for Children 3-5

Pre-school programs help your child's development continue. Like all public education, these programs must be offered in the "least restrictive environment" whenever possible. This means in classrooms with students who have no disabilities. Call your local public elementary school to set up a free evaluation.

### School-Age Programs for Children Over 5

Programs can be offered in settings (classrooms) with other students or in separate settings. Picking the right place depends on your child's needs.

### Individualized Education Programs (IEPs)

IEPs outline the goals for a child all through the preschool and school-age years. The IEP will:

- Be developed together by parents, teachers and other specialists
- Say what setting the child will be taught in
- Explain what services and assistive technology the child will get
- Be as detailed as possible
- Be reviewed regularly and changed, if needed

### The Individuals With Disabilities Education ACT (IDEA)

Requires all states to provide a free, appropriate education to children with disabilities ages 3 through 21. It also requires EIPs for infants and toddlers with disabilities.

**You can really help your child by getting involved in their education!**

## Some Questions and Answers

Help is also available from many state and local agencies.

For a person with CP, loving care and understanding can make a big difference!

### **If I have another child, will they also have CP?**

It's not likely. It's a good idea to find out what caused CP in your child. Then you can find out if CP can be prevented in future pregnancies.

### **What support is available for parents?**

Look into local parent support groups and programs that help families. Ask your child's health care provider about groups in the area. Or, check the phone book for social service agencies in your area. Family and friends are another important source of support. Be sure to reach out to these people for help.

### **Where can I get more information about CP?**

Visit your local library. And, contact these sources:

- United Cerebral Palsy Associations (UCPA) **1-800-872-5827**
- The National Information Center for Children and Youth with Disabilities (NICHCY) **1-800-6954-0285**
- National Easter Seal Society, Inc. **1-800-221-6827**
- American Academy for Cerebral Palsy and Developmental Medicine [www.aacpdm.org](http://www.aacpdm.org)
- Cerebral Palsy Alliance <https://www.cerebralpalsy.org.au/about-cerebral-palsy/>
- CP Now Foundation <https://cpnowfoundation.org/>

## Get All the Information You Can About CP

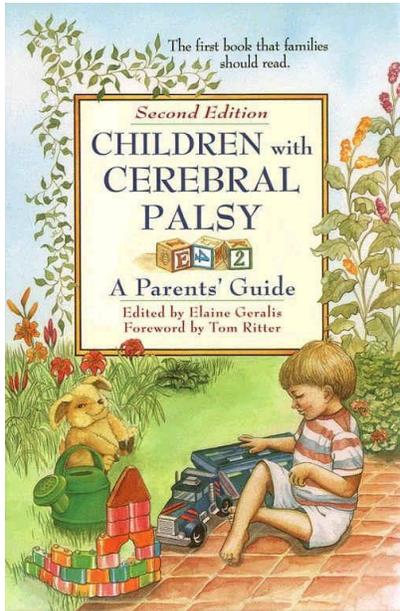


- ☑ **Understand** how CP can affect a person.
- ☑ **Recognize** the benefits of early therapy and management.
- ☑ **Take advantage** of early intervention and management services.
- ☑ **Help** the person with CP reach their full abilities.



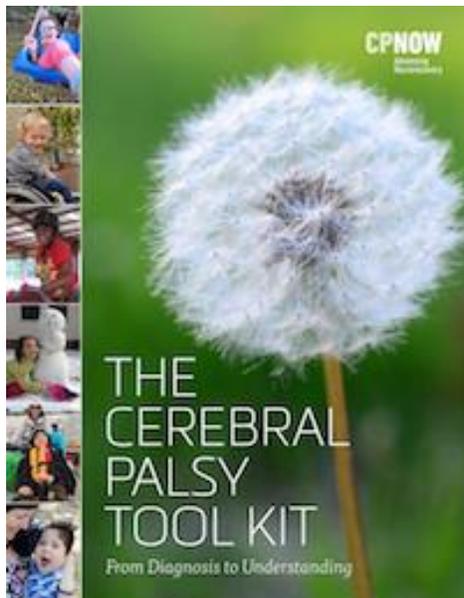
## More Helpful Resources

Find this book at your library, or at your local bookstore. You can also order it online.



You can find this toolkit at the CP Now Foundation

<https://cpnowfoundation.org/>



Download the CP Channel App from the Cerebral Palsy Foundation

### INTRODUCING THE CP CHANNEL

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