



— KNOW —

C E R E B R A L

P A L S Y



What is cerebral palsy (CP)?

Cerebral Palsy (CP) is a neurological condition that affects body movement, muscle tone, and posture. The terms 'cerebral' refers to the brain and 'palsy' refers to impairment in muscle function.

CP is caused by an early brain injury (before, during or after birth), specifically in the part of the brain that controls muscle functions. The damage to the brain is permanent and cannot be reversed. The impact of cerebral palsy varies from child to child.

While there is no cure for cerebral palsy, there are various therapies and interventions available to help improve quality of life of children with the condition so that they can be as active and independent as possible. Cerebral palsy poses different challenges in different children, but it doesn't mean they can't grow up to be happy and healthy.

What does cerebral palsy look like?

Children with CP may have involuntary movements, poor balance & coordination, increased (tightness of muscles) or decreased muscle tone (loose muscles) or a combination of these. In some it may affect the whole body, while in others, it might only affect one or two limbs or one side of the body. The most common type is spastic CP (tightness of muscles) which occurs in 80% of cases.

In some children, CP can also lead to co-occurring conditions like seizures, visual and hearing impairment, behavioural difficulties, and intellectual disabilities (low IQ levels). Cerebral palsy is a diverse condition and each child's experience is unique. Some children may have symptoms ranging from mild tightness of some muscles of their hands or legs and be able to walk independently, while others may require assistive aids, and some may need lifelong care.

What are the early signs of cerebral palsy?

CP is typically diagnosed during the first or second year after birth. Parents may observe that their infants have difficulties in sucking, swallowing and frequent bringing up of their feeds, excessive drooling, abnormal movement of the eyes, excessive crying and irritability, not being visually alert and/or show poor response to sound. Other signs include:

1

Developmental delays.

The child is slow to reach milestones such as head holding, rolling over, sitting, crawling, and walking.

2

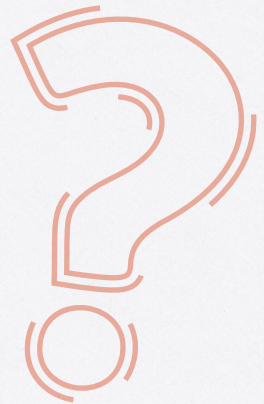
Abnormal muscle tone.

Body parts are either floppy or too stiff. Caregivers often notice these tone abnormalities while lifting the child, diapering and dressing.

3

Abnormal posture.

The child might also use one side of the body more than the other when reaching, crawling, or moving.



How is cerebral palsy diagnosed?

Symptoms of cerebral palsy become apparent over time. The diagnosis of cerebral palsy is based on history provided by the caregiver and a detailed clinical evaluation by a doctor like a paediatrician, paediatric neurologist, or developmental paediatrician.

The process of diagnosis begins with a complete history of pregnancy, birth, and early infancy. A thorough physical examination of the child is done where the doctor looks closely at the child's movement, muscle tone, reflexes, and posture.

Tests such as MRI, EEG, blood evaluations and genetic tests are done in order to identify the underlying cause or associated co-occurring conditions, if any. An orthopaedic referral is made if hip, spine or joint involvement is suspected.

The goal of the diagnostic process is to identify the cause and type of cerebral palsy, so that one can start appropriate interventions and support.



What are the other co-occurring conditions with cerebral palsy?

There are other conditions that arise as a result of having cerebral palsy, which if not monitored or treated, can often become challenging. A child may not have all of them, however it is likely that they will have some of these issues and it is important to identify them to make sure that treatment and support starts on time.

Typical co-occurring conditions include:

- 1 — Problems with bones, joints, hip & spine development and alignment
- 2 — Pain
- 3 — Breathing problems and increased risk of chest infections and respiratory issues
- 4 — Increased chances of seizures and epilepsy
- 5 — Vision and hearing issues
- 6 — Communication and speech issues
- 7 — Feeding issues leading to concerns around proper nutrition
- 8 — Issues in bladder and bowel control
- 9 — Gastrointestinal issues such as reflux or constipation
- 10 — Sleep issues due to pain or posture
- 11 — Excessive weight gain
- 12 — Learning disabilities or intellectual disabilities
- 13 — Behaviour & emotional problems



I have just received a cerebral palsy diagnosis for my child. What should I do?

Getting a final diagnosis of cerebral palsy is an emotional time. You may feel guilt, grief, or anger. You may fear what it means for your child's future and feel overwhelmed about where to begin to support your child's development. All these emotions are perfectly natural, and you should give yourself time to process these feelings. Seek support from friends, family, or support groups for parents of children with cerebral palsy. Connecting with others who have gone through similar experiences can provide valuable insights and emotional support. Keep an open and positive mind about your child's development while also reaching out for the support and treatment your child may need. There is no denying that in the beginning, this journey appears hard, but with professional guidance, you will move forward, and also discover your inner strength.

Do remember that a CP diagnosis does not define your child or their future. Rather, it enables you and the medical team to figure out the specific interventions that will make a difference for your child.

What kind of treatment and interventions does my child need?



A child with CP requires comprehensive care by a multidisciplinary team that includes a paediatrician or developmental paediatrician, paediatric neurologist, occupational & physio therapists, and other specialists (orthopaedic, gastrointestinal, vision, hearing, mental health etc), as needed. They collaborate to develop a personalized treatment plan for the child.

The overall goals of the treatment plan are:

- Improving your child's mobility to the greatest possible extent and gain independence.
- Preventing and managing any complications.
- Making sure your child's nutrition and overall health is taken care of.
- Maximizing your child's ability to participate and be involved actively in activities at home, at school, and in the community.
- Making changes in the child's environment to support them and improve participation.

Please know that the human brain is amazing, and all children can learn and progress!

The ability of the brain to rewire itself and create new neural connections, so that the functions affected by brain damage can be compensated is known as **'Neuroplasticity'**. Though neuroplasticity can happen at any age, early intervention can greatly improve outcomes, as the ability of the brain to adapt to new learnings is maximum in the early years of life. This happens through therapies that help by teaching children the skills that are difficult for them, through small steps and repeated practice.

Generally prescribed therapies and support include the following:

Physiotherapy:

Focuses on improving mobility, muscle strength, flexibility, balance, coordination, and overall motor function. Techniques used may include stretching exercises, strengthening exercises, working on balance, gait, and posture. It helps in developing stronger muscles such as those of trunk and limbs and works on skills such as rolling, sitting, walking etc.



Occupational Therapy:

Increases a child's ability to participate in daily activities, improve fine motor skills, and develop independence in self-care tasks. The goal is for the child to participate as actively and independently as possible in all areas of daily living such as dressing, feeding, writing etc.

Speech therapy:

Addresses concerns with swallowing, feeding and speech. Oral motor exercises can improve the ability to chew and swallow food, reduce drooling and to speak clearly.



Orthotics & assistive equipment:

Orthotics are devices that are worn externally on the body to provide support, stability, alignment, or correction. They encourage mobility, balance, and proper physical growth. Some examples include splints, braces, casts, custom designed shoes. These help to prevent impairment of joints and contractures (shortening and hardening of muscles). Assistive equipment includes wheelchairs, walkers etc. which help children with independence & access.

One may explore many other options which encourage movement in a fun way such as art-based therapy, music & dance therapy, animal assisted therapy or even just playing in the playground. Children learn best in natural settings. If one has access, aquatic therapy (exercises & activities performed in a warm-water pool) is a great way to improve muscle strength, flexibility, and relaxation.



Another important aspect of care in cerebral palsy is **Pain Management**. Many children experience chronic pain due to muscle spasms & stiffness or other issues. Pain management can include pain relieving medicines, muscle relaxants, Botox, or therapeutic approaches such as physiotherapy, massages, cold or heat therapy, hydrotherapy etc.

Caregivers can play a key role in monitoring for signs of pain, learning to deliver some pain management techniques such as massages and advocating for their child's needs with specialists. Encouraging children to express their discomfort can help ensure their pain is adequately addressed.

How do I manage nutrition of my child?

Children with cerebral palsy have problems with chewing and swallowing food, regurgitation (reflux) and may even have choking and coughing episodes. Acid reflux is also more common in them, leading to stomach-ache, nausea, vomiting and arching postures. These factors, combined with increased feeding time, may lead to malnutrition, deficiency of macro and micronutrients resulting in impaired growth in these children.

It is advisable to learn positioning and feeding techniques to make mealtimes easier and safe for the child and caregiver. If feeding problems persist and the child is unable to eat food orally, they may need to be given food through a tube.



Will my child go to school?



The Right to Education Act, 2009 guarantees access to school and barrier free access for all children, including children with disabilities. Children with cerebral palsy should and do go to school.

The choice of school will depend on the individual needs and abilities of the child. Options include a mainstream school, an inclusive school (welcomes all children irrespective of abilities), special schools (meant specifically for children with disabilities), homeschooling (by family or tutors or at a study center).

Understand strengths, challenges, and specific needs of the child. Consider factors such as mobility, communication abilities, cognitive skills of the child, and accessibility, resources, and inclusive practices of the school. Whatever decision you take, child should be able to receive support, encouragement, and opportunities to participate fully. With the right support and resources, children with cerebral palsy can and do thrive academically and socially in various school settings.

How can I help my child?



Cerebral palsy (CP) affects each child in a different way, so no two families have the exact same experience in their child's care. Although CP is a lifelong condition that can't be reversed, with proper support & care, children with cerebral palsy can lead rich, fulfilling lives. Whether your child has mild or severe CP, there are several ways that you can help them do their best.

Be an active participant in their treatment planning:

Your child may see many health care providers, from pediatricians to specialists to therapists and beyond. Keep organized records of your child's medical history and reports. Establish a central point of contact, usually the child's pediatrician or developmental pediatrician, through whom you can update and evaluate care that is received elsewhere. Share your insights about your child's progress and challenges. You will rely on the experience of professional experts, but you know your child best, and they will come to rely on you to tell them about his or her specific challenges and needs. Take shared decisions by asking questions and having discussions with your child's care team.

Encourage physical activity:

It is important to get your child to be active to the best of their ability. Help them walk (if they can), play, and move as much as possible. Teach them new skills, so they may use their muscles in new ways. Incorporate fun and enjoyable activities such as swimming, cycling, dancing, or yoga at an early age, so one can continue it in adolescence.



Be your child's at-home therapist:

Therapy room is not just for the child, but a space for you to collaborate with the therapist on home programs. Techniques and exercises learnt in the therapy room can be incorporated in the child's daily life at home, which not just supplements the therapy, but also moves it to natural settings, which is important. Moreover, a parent brings a multi-disciplinary approach as they work on aspects of various therapies such as speech, physio, ortho, behaviour, in what they do at home.



Creating a balanced therapy program:

There are times when intensive treatment is needed to achieve goals, but if you are feeling overwhelmed with different treatment visits, your child probably feels it too. Create a schedule that is appropriate for you and your child. When you are evaluating treatment options and goals, think in practical terms about what will help your child to move, to play, to learn and participate in life at home, in school and in the community. Make therapies fun, engaging and meaningful for the child. Give them space to explore what they like and integrate their interests with opportunities for development e.g., cooking or baking could be equally great at promoting movement.



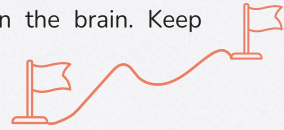
Encourage social interactions:

Create opportunities for your child to interact with siblings, friends, or classmates or peers in supportive settings. These could be playdates, outings with family or friends, or group therapy sessions. Social interactions and building relationships with peers are important life skills.



Keep a bright outlook:

Every child progresses at their own pace. Their future abilities cannot be known, nor the time frames in which goals will be achieved. Focus on your child in the present and help them build on emerging skills. Celebrate all achievements, big and small. Be patient many repetitions are necessary to promote adaptive changes in the brain. Keep practicing and trust in the process.



Focus on your own well-being and mental health:

Parenting a child with cerebral palsy can be tough. For some of you this may be your first time feeling that you need some assistance working through your feelings or problems. There is no shame in seeking professional help. The better care you take of yourself, the more energy and strength you will have for your child. Carve out times during the week to do things you enjoy or simply be with your child or other family members without thinking about CP.



Connect with other parents:

The most important thing you need to know is that you are not alone. There are many other families dealing with similar challenges. Get to know other parents of children with cerebral palsy. They can be a great source of helpful information, advice and emotional support.



Additional Resources

Family Resource Center (FRC) at Ummeed is a team of parents of children with disabilities, who are available to offer support to and guide on available information and resources.

Please connect with the FRC team via email: **frc@ummeed.org** or phone: **8591850804**

- To talk to another parent
- To get support, suggestion, insights, and advice
- To be a part of a parent support group that meets once a month (English or Hindi)
- To stay connected with a community of families
- To participate in fun & recreational activities

Training Programs at Ummeed:

Ummeed conducts many training programs for parents of children with disabilities. View on <https://ummeed.org/all-coursesor> ; e-mail: **training@ummeed.org** ; or send a WhatsApp message on **85912 91603** to know more.

Developmental Disabilities India (DDI):



Developmental Disabilities India is a new YouTube channel dedicated to awareness about developmental disabilities. It has informative videos on various disabilities along with tips-based videos by parents and professionals.

Watch video by Dr Roopa Srinivasan on **'What is Cerebral Palsy?'**



Books

- Cerebral Palsy: From Diagnosis to Adult Life, *Peter Rosenbaum and Lewis Rosenbloom*
- Cerebral Palsy: A Complete Guide for Caregiving, *Freeman Miller and Steven J. Bachrach*
- Children with Cerebral Palsy: A Parent's Guide, *Elaine Geralis*
- Unbeatable – Celebrating Life with Cerebral Palsy, *Shukhi Sharma (Parent Authored)*

Online

- <https://www.cerebralpalsyguide.com/>
- <https://cprn.org/> (Cerebral Palsy Research Network)

Organizations/Parent Support Groups

- ADAPT <https://www.adaptssi.org/>
- Cerebral Palsy Association of India <https://cpai.org.in/>
- Nayi Disha Pan India Parent Support Group for Cerebral Palsy
<https://nayi-disha.org/parent-community/>



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