

Indian Academy of Pediatrics (IAP)



GUIDELINES FOR PARENTS

Home Care of a Child with Cerebral Palsy



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10 FAQs on HOME CARE OF A CHILD WITH CEREBRAL PALSY

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Home Care of a Child with Cerebral Palsy

Q1

What is “Cerebral Palsy”?

Cerebral palsy, sometimes referred to as CP or spastic child, refers to a group of disorders affecting a person’s ability to move, maintain balance and posture, and perform day-to-day activities. *Cerebral* means having to do with the brain, and *palsy* implies weakness or problems with muscles. Simply put, cerebral palsy is caused by abnormal brain development or damage to the developing brain that affects a child’s ability to control their muscles. The brain injury causing cerebral palsy may also lead to other issues such as seizures, visual and hearing impairment, intellectual disability, and behavioral problems. The symptoms of cerebral palsy vary greatly from one child to another, depending upon the severity of the damage, associated comorbidities, and complications.

The disease does not worsen with age; there may be changes in the clinical expression depending upon brain maturation and timely intervention by treating doctors.

Why does “Cerebral Palsy” occur?

Cerebral palsy results from abnormal brain development or injury to the developing brain, caused by many factors. About 80% of these insults responsible for cerebral palsy occur before delivery, 10% happen around the time of birth, and the remaining 10% happen in early childhood.

Insults Happening before Birth

- *Abnormal brain development:* Identified in approximately 10% of children with cerebral palsy.
- *Maternal factors:* Poor nutritional status of the mother, maternal infections being transmitted to the fetus through the placenta, uncontrolled blood pressure (eclampsia), and drug use (antiseizure medications, alcohol, smoking/nicotine, and cocaine) in the mother may cause cerebral palsy.
- *Genetic factors:* A positive family history of cerebral palsy, consanguineous marriage in parents, and presence of other congenital anomalies point toward genetic abnormalities.
- *Placenta-mediated complications:* Poor blood supply across the placenta impairs the baby's growth in utero, and a low birth weight baby is at a higher risk for cerebral palsy.
- *Multiple pregnancies:* The relative risk of cerebral palsy is much higher in twin and triplet pregnancies.
- *Gestational age:* Prematurity is the most important risk factor for cerebral palsy with 10% of neonates born extreme preterm (<28 weeks) developing cerebral palsy.

Insults Happening at the Time of Birth

- Prolonged and difficult labor, bleeding from the birth canal before delivery, or the presence of fetal heart rate abnormalities.
- Delivery by emergency Caesarean-section (C-section) and baby having passed stool (meconium) prior to delivery are other risk factors.

Insults Happening at Immediately Postdelivery

- Low blood sugar can adversely affect the neonatal brain and cause cerebral palsy.
- Neonatal infections, especially brain infection (called meningitis or encephalitis).
- Brain damage due to very high bilirubin levels in a jaundiced neonate (kernicterus).
- A brain bleed or stroke occurring due to blockage of blood vessels supplying the brain.

Insults Happening in Early Childhood

Infections of the brain (meningitis/encephalitis) or any event leading to impaired oxygen supply to the brain till about 2 years of age, including head injury, prolonged seizures, and acute life-threatening episodes such as drowning, can predispose to cerebral palsy.

Q3

What are the symptoms of cerebral palsy? What are the associated problems?

The symptoms of cerebral palsy vary depending upon the type and severity of the brain injury. They may change considerably as the child's age increases and brain functions mature. The average age at diagnosis is 18–24 months when parents start noticing the most evident symptom of delay in attaining motor milestones such as sitting independently, crawling, or walking. Regular follow-up with a pediatrician can detect cerebral palsy early at 6–9 months. So, well-baby visits in infancy may be key for early diagnosis and intervention to prevent disability because of cerebral palsy.

Early Signs

Problems that start manifesting shortly after birth are difficulties in breastfeeding and frequent regurgitation of feeds, excessive irritability, poor sleep, abnormal stiffness or looseness of the body leading to problems in holding or cuddling the baby, and inability to focus on or follow toys or faces.

In a baby younger than 6 months, important signs are trouble holding up head when picked up, stretching of back and neck while being held, which gives the impression of the child pushing away from parents and crossing, stiffening of legs when picked up (scissoring) all of which are due to inappropriate muscle control leading to weakness or stiffness of different muscles.

Signs Noticed after Infancy

These signs can be grouped into *positive signs* leading to increased stiffness of muscles (noticed while massaging the baby or changing diapers) accompanied by unwanted, uncontrolled involuntary movements, and *negative signs* which reflect insufficient muscle activity such as fatiguability, weakness, slow and effortful voluntary movements, and difficulty in performing activities requiring dexterity or fine motor control.

Different patterns of body involvement have been described correlating with the area of brain damage with some children having predominantly lower limb weakness and good hand function (*spastic diplegia*), weakness of one side of the body (*spastic hemiplegia*), or the more severe variant affecting the function of all four limbs (*spastic quadriplegia*). In some patients, the clinical picture may be dominated by abnormal involuntary movements and postures (*dyskinetic cerebral palsy*).

Associated Problems

In addition to the problems with movements and posture, also impaired are other body functions governed by muscular control or motor skills such as swallowing and chewing, leading to problems with eating, breathing, bowel and bladder control, and speech. The brain injury causing cerebral palsy may also lead to other brain function disorders with abnormalities affecting intelligence, vision, hearing, language, perception of sensations, attention, and behavior.

- *Nutrition and growth*: Children with cerebral palsy have problems with chewing and swallowing food and may sometimes even have choking and coughing spells while

feeding along with regurgitation of feeds. Acid reflux is also more common in them, leading to stomach ache, nausea, and vomiting. These factors, combined with increased feeding time, contribute to malnutrition, deficiency of micronutrients, and impaired growth in these children. If feeding problems persist despite medical management, they may need to be given food through a tube inserted into the nose or directly into the stomach to improve their nutritional status.

- *Seizure disorder/epilepsy*: Epilepsy occurs in 25–45% of patients with cerebral palsy, with seizures presenting as abnormal jerking movements, generalized stiffness of the body, vacant stares, etc. Epilepsy can impose an additional hurdle, when it is difficult to control or if antiseizure medications cause sedation, further impairing learning and socialization.
- *Intellectual disability* is seen in more than half of the kids with cerebral palsy.
- *Neurobehavioral/neurodevelopmental disorders*: Patients with cerebral palsy commonly have behavioral, emotional, and psychiatric disorders, including emotional lability, poor attention span, anxiety, obsessive-compulsive, and sometimes autistic traits.
- *Visual disorders*: Children with cerebral palsy often have trouble seeing due to visual fixation problems and may also have obvious malalignment of eyes (one or both eyes turning in or out).
- *Hearing impairment*: Hearing impairment occurs in 10–20% of children with cerebral palsy, and about 5% are deaf. Early diagnosis (by 3 months) and treatment (by 6 months) of hearing loss in these kids is vital for learning and language development.
- *Speech and communication problems*: Disorders of speech and language are seen in 40–60% of children with cerebral palsy, and about 25% are entirely nonverbal.
- *Bowel and bladder control*: Due to ineffective muscular control, bowel and bladder functions are both impaired. Constipation is a troubling factor for the kids and parents with infrequent and irregular bowel movements or straining and crying excessively while passing stools and passing hard stools. Similarly, bladder control is also compromised in some patients with incomplete voiding of urine, incontinence, and recurrent urinary tract infections.
- *Respiratory disorders*: The muscles responsible for breathing may also become affected, leading to uncoordinated movements. Combined with the additional problem of food aspiration into the respiratory tract, these children are at a higher risk for recurrent chest infections and resultant chronic respiratory insufficiency.
- *Problems related to bones and joints*: Common orthopedic problems include abnormal curvature of the spine (scoliosis), foot deformities, dislocation of the hip joint, and contractures across various joints limiting the range of motion. There is also decreased bone density putting them at an increased risk for fractures.
- *Excessive drooling of saliva*: This can be attributed to poor muscular control of swallowing, leading to difficulty in managing oral secretions, and impacting feeding and oral hygiene.
- *Poor sleep*: Sleep in kids with cerebral palsy is very often impaired with difficulty in falling asleep, frequent awakenings at night, and overall poor quality of sleep, which may worsen coexistent behavioral issues and hamper efficiency at daytime activities like learning.
- *Pain*: Pain is reported in 50–75% of children with cerebral palsy but may go unrecognized in many of them due to communication difficulties. It may be due to multiple factors such as muscle stiffness, involuntary movements, acid reflux, joint deformities, and constipation.

Q4

Are there any tests for diagnosing cerebral palsy?

Cerebral palsy can be diagnosed solely based on parents' history and a thorough clinical examination (especially during well-baby visits in infancy as scheduled). Tests are not required to establish the diagnosis; but they may be needed to determine the underlying cause and/or associated comorbidities. These tests include an MRI of the brain, blood tests for metabolic or genetic disorders, and tests for abnormal blood coagulation. For identifying related comorbidities, the following may be performed:

Electroencephalogram (EEG)

An EEG is a test that measures the brain's electrical activity and helps to diagnose seizure disorder. It is indicated if the child has a history of seizures/fits and in children without any apparent history of seizures but not gaining any milestones on follow-up (to rule out any ongoing seizure activity with subtle clinical seizures which are not appreciated by parents/caregivers).

Hearing Assessment

Hearing impairment co-occurs with cerebral palsy in 10–20% of children. Early identification followed by timely intervention can improve their language, communication, and cognitive skills. Universal newborn hearing screen by 1 month of age for all babies and before discharge from nursery for sick babies is a routine now. All babies referred after screening should undergo diagnostic auditory brainstem response (ABR)/brainstem-evoked response audiometry (BERA) by 3 months. However, if not already done, a formal hearing evaluation by audiometry and BERA is indicated in all children with cerebral palsy before 24 months of age or even sooner, if there are any clues toward hearing loss like inability to react to loud environmental noises, not responding when spoken to, and not turning toward familiar sounds.

Visual Assessment

Problems with vision occur in 30% of children having cerebral palsy and can range from refractive errors (eye cannot focus images), visual field defects (restricted area in which images of objects can be perceived), cortical blindness (child can see, but the brain cannot interpret the images), and squint (obvious deviation or malalignment of eyes) to cataracts (opacification of the eye lens). The goal of visual testing is primarily to determine, if the child can see and, if so, to estimate the level of visual acuity. A comprehensive eye evaluation is required to identify

any correctable disorders. A test called visual-evoked potential (VEP) may sometimes be advised to look for brain's response to visual stimuli. All premature babies (also at risk of cerebral palsy) are routinely screened for retinopathy of prematurity.

Intelligence Quotient and Behavioral Assessment

Almost half of the patients with cerebral palsy have intellectual disability, which implies that 50% have near normal intelligence and with brain-saving newborn care strategy, proportion of children with intact intelligence is likely to rise. In addition to the developmental screening done at every follow-up visit for the attainment of milestones, appropriate developmental assessments and behavioral assessments may be indicated on an individualized basis, e.g., a child gaining motor milestones but not interacting with family members or peers and having a delay in speech may need to be screened for "autism spectrum disorder".

Speech and Language Disorders

Disorders of speech and language are very common in children with cerebral palsy. Screening for these problems should be done at routine outpatient department (OPD) visits by looking at the ability to understand and follow simple commands and interact appropriately in different settings. If a delay is suspected, a formal speech and language assessment is warranted.

Q5

Why cannot my child feed properly?

A child with cerebral palsy may not feed properly because of the following reasons:

- Improper sucking, which may be the first sign of cerebral palsy, may occur due to pushing out of the tongue, floppy inactive lips, and/or uncontrolled body movement. Children with cerebral palsy have specific problems with swallow coordination resulting in the risk of aspiration.
- Exaggerated gag reflex
- Exaggerated bite reflex
- Tactile hypersensitivity

Due to the above points, the parents need to have more patience because mealtime is longer than usual. Since inception, you need to practice feeding your child with adequate nutrition according to his physical age and not mental age. The different positioning of a child while feeding and sitting arrangements are depicted in **Figures 1 and 2**.

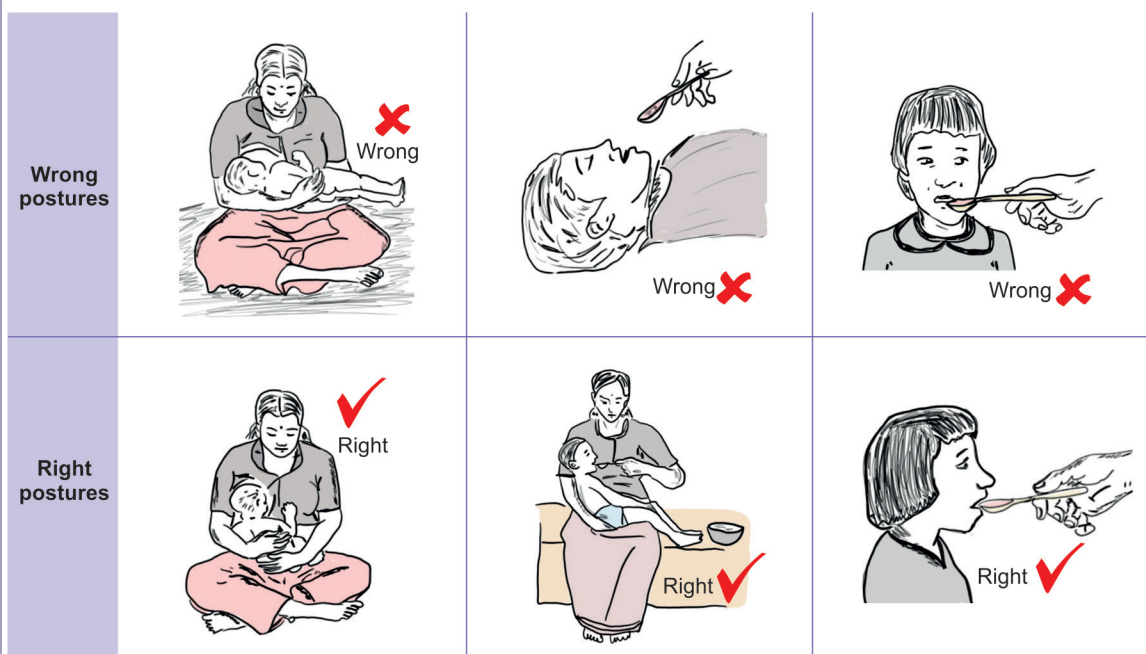


Fig. 1: Wrong and right postures for feeding.

Source: Illustration by Mad About Design: www.madaboutdesign.co.in



Fig. 2: Options for sitting arrangements during feeding.

Source: Illustration by Mad About Design: www.madaboutdesign.co.in

Q6

My child drools a lot. What can I do about drooling?

Typically drooling control comes at 15–18 months. Persistent saliva drooling beyond 4 years happens due to inadequate swallowing reflex and inefficient control of salivary secretions rather than overproduction. Visible saliva spilling from the mouth lowers self-esteem, stigmatizes, interferes with speech, dampens cloth, damages utilities, and irritates the skin. *Posterior drooling* that is spilling of saliva in the pharynx poses a risk of aspiration and pneumonia. You need to consult a counselor, occupational therapist, psychologist, and pediatrician for management of the same.

Tips for helping children with drooling:

- Towel wrist-band to self-wipe
- Dabbing firmly is better than wiping across the mouth and chin
- Neckerchief is more appropriate for the age.
- Avoid sweet drinks which increase saliva and use intraoral devices if needed.

The common strategies for managing drooling are illustrated in **Tables 1 and 2 (Figure 3)**.

TABLE 1: Management of drooling of saliva.

<i>Anterior drooling</i>	<i>Posterior drooling</i>
<ul style="list-style-type: none"> • Conservative • Oro-motor—sensory strategies • Behavioral • Oral appliances* • Oral medication* • Injections* • Surgical* 	<ul style="list-style-type: none"> • Postural • Oral medications* • Injections* • Surgical* • Radiotherapy*
*Consult your pediatrician	

TABLE 2: Management strategies for drooling.

Conservative Management	
Management of underlying problem	<ul style="list-style-type: none"> • Treatment of nasal obstruction • Occupational therapy for postural deformities • Modification in the wheelchair to support the head • Repositioning of computer screens and other devices
Helping children control salivation and oral movements	<ul style="list-style-type: none"> • Developing eating skills • Lip closure and tongue movement • Behavioral—by teaching a sense of wetness and be able to swallow or wipe saliva frequently • Exercise and games • Use of various facial expressions • Lip articulations—bbb, mmm, ppp • Kissing on a mirror or tissue games • Blowing musical instruments/candles • Holding paper-spatula between lips • Sucking liquid through plastic tubes • Devices—oral screen, lips vibrators
Eliminating mouthing behavior	<ul style="list-style-type: none"> • Diverting attention—preferred • Wearing gloves • Applying bitter, unpleasant substances • Elbow splint
Encouraging to swallow and wipe	<ul style="list-style-type: none"> • Verbal reminders—show them mirror • On each swallow and wipe, reward • Touch cues • Visual cues • Auditory cues—accularms
Improving oral health	<ul style="list-style-type: none"> • Optimizing oral hygiene • Regular professional advice • Using scarf/customized clothing


Fig. 3: Improving oral functions to reduce drooling.

Q7

My child does not pass stool properly; what should I do?

Constipation in a cerebral palsy child is due to poor dietary intake, especially fibers, postural deformities, decreased mobility, and also muscle spasm.

- The longer stool remains in the colon, harder it becomes. Toilet timing and training should be such to motivate the daily passage of stool. Give sufficient time, at least 10 minutes. They can also be trained to squeeze the muscles of their stomach.
- Support your child to be upright on waking up and while eating because gastrocolic reflex is more prominent in an upright posture. In an upright posture, gravity also plays a role. Eating or bathing for 15 minutes, also stimulates bowel movement.
- The toilet seat should be appropriate in size with a footrest. A rail to hold on will keep them more secure.
- You can also ask your child specialist to provide laxatives.
- Dietary intake should have an adequate amount of fiber. An excessive amount of cheese, milk, and bananas should be avoided.

Daily fiber intake in child = Age in years + 5 g

Parenting Skills for Toilet Training

- Toilet training should not be delayed but not earlier than when your child is ready (usually around 3–4 years). Train them to “stay dry” and “stay clean”.
- Put the child on the seat just before the presumed set time.
- Reward and praise—Clap your hands or give a kiss; make sure that the child knows that you are pleased. Please do not offer sweets as a reward.
- Train with the help of models, dolls, and demonstrations. Guide your child with movements of your hand and not tongue like lowering pants, showing stool seats, and passing stool and urine with the help of dolls.
- Customize the clothing and toilet seats according to their needs (**Fig. 4**).

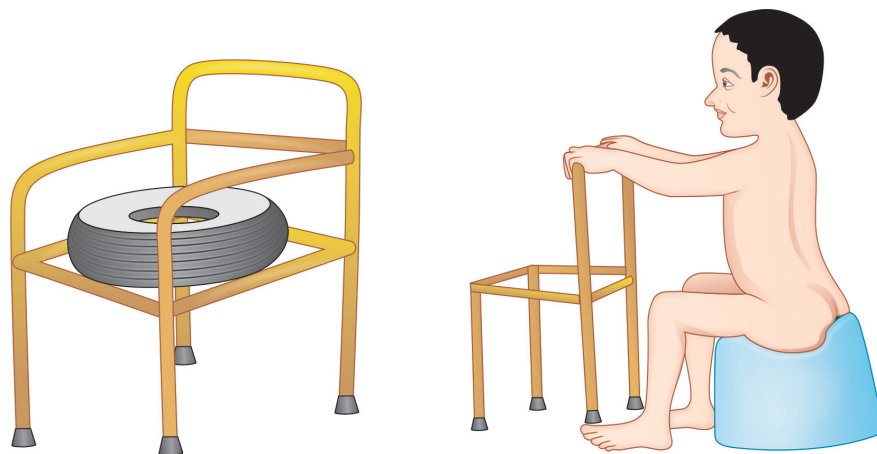


Fig. 4: Customization of toilet seats.

Q8

Can cerebral palsy be cured? What medicines will my child need?

Cerebral palsy is a permanent disorder resulting from an insult that happens early on in life. Though the disease itself is nonprogressive and does not worsen with the child's age, the already present features of the disease cannot be cured completely.

But with adequate training, exercises, and medications, the children learn to function well, become independent with respect to day-to-day activities such as eating, speaking, learning, and walking, and achieve a good quality of life.

- **Positioning:** A commonly encountered problem is stiffness or weakness of certain body parts and some unwanted, uncontrolled, and involuntary movements that you may notice in your child. They may be a source of discomfort and pain to the child and may interfere with everyday activities and functionality. It is essential to position the child appropriately while making him/her sit or stand. These positioning maneuvers will help in reducing stiffness in many circumstances. Common positioning suggestions are highlighted in **Figure 5**.
- **Drugs:** Also, medications can help in relaxing the taut muscles, improving the posture, and relieving the discomfort while minimizing unwanted movements. Some of the medicines used for this purpose are baclofen, tizanidine, and pacitane. They work the best when combined with the use of specially fitted shoes (orthoses) and physiotherapy. If the stiffness persists, despite using these oral medications, injection of botulinum toxin into the stiff muscle groups helps to improve the range of motion.
- **Seizures/fits:** If your child has a seizure, he/she may need to be started on antiseizure medications such as sodium valproate, levetiracetam, phenytoin, clonazepam, or clobazam to control any ongoing seizure activity in the brain and to prevent a recurrence. These medications require strict compliance, and you would be required to follow up at regular intervals.
- Cerebral palsy is associated with *behavioral problems*. The child may be excessively irritable, stubborn, prone-to-temper tantrums, hyperactive, or aggressive. He may also show repetitive, stereo-typed movements and, in severe cases, lack of awareness of danger and self-injurious behavior. In these cases, depending on the pervasive behavior pattern, medications would need to be prescribed to help him cope better, in addition to behavioral therapy.

- **Sleep issues:** Sleep in kids with cerebral palsy is often impaired with difficulty falling asleep, frequent awakenings at night, and overall poor quality of sleep, which may worsen coexistent behavioral issues and hamper efficiency at daytime activities like learning. Sometimes, drugs may help to overcome sleep latency and improve the overall duration and quality of sleep, apart from drugs.
- **Nutrition:** Children with persistent feeding problems may need to be given food through a tube inserted into the nose or directly into the stomach to improve their nutritional status.
- **Constipation:** In addition to dietary modifications, stool softeners such as lactulose or sometimes laxatives may be needed to regularize bowel habits. Similarly, bladder control is also compromised in some patients with incomplete voiding of urine, incontinence, and recurrent urinary tract infections. Though behavioral and lifestyle modifications and treatment of constipation help in the majority, in some cases, medications such as oxybutynin may need to be prescribed.



Fig. 5: Handling and positioning of a child with cerebral palsy.

Source: Illustration by Mad About Design:
www.madaboutdesign.co.in

Q9

What will my child be like? Will he be able to walk/sit?

It is important to realize that though children with cerebral palsy will not be able to do all the things that their siblings/peers can, the emphasis should be on things that they can do on their own or with some help than the limitations.

Ability to Walk and Sit

- On average, approximately 60% of children with cerebral palsy can walk independently. Another 10% can walk with the help of a mobility device. The answer to these questions is likely to become clear by about 2 years of age.
- If the child can sit independently at 2 years, it is expected that child will be able to walk by 6 years. If a child cannot sit but can roll at 2 years, there is a possibility that child may be able to walk unaided by 6 years.
- Children who are unable to sit by 4 years rarely walk.
- There are other factors also influencing ambulation, like the type of cerebral palsy wherein children with hemiplegic cerebral palsy (affecting one-half of the body) most often start walking by 2 years, and more than half of children with spastic diplegia (affecting legs predominantly) learning to walk independently.
- The presence of cerebral palsy involving all four limbs, associated visual impairment, or seizure disorder indicates that the child is unlikely to walk.
- Early and regular physiotherapy, use of medications to relieve stiffness in muscles, and use of ambulatory assist devices greatly enhance independent ambulation chances.

Speech

Majority of children catch up with speech therapy, and the use of electronic speech-generating devices, talking typewriters, Bliss symbols, etc.

Cognitive Ability

Intellectual disability is also present in a significant proportion of kids with cerebral palsy, and the learning experience for them will have to be individualized. While some children may adapt to the mainstream educational system, the learning system may have to be modified for the rest to make sure they feel included and to promote their sense of independence, self-reliance and to help inculcate social skills. The options available to them could be self-contained classroom programs, special educational centers, shadow teachers, home-schooling, or vocational and occupational learning programs.

Life Expectancy

Children with mild forms of cerebral palsy often live as long as people who do not have the disorder, but children with more severe forms may have a shortened lifespan. The more severe the child's physical, functional, or cognitive impairment, the more the effect on life expectancy. The movement-related disabilities, feeding problems, seizures, and recurrent lung infections are essential variables in determining lifespan.

An attempt should be made toward improving their overall quality of life by enhancing mobility, maximizing independence in daily activities, alleviating any pain or discomfort, promoting learning, communication, societal associations and interactions, and treatment of any comorbidities or complications.

Most children with cerebral palsy can live long, happy, and quite normal lives with these endeavors.

Q10

Can this affect my next child as well? How can I take precautions about it?

Cerebral palsy in next baby is very unlikely. The risk of recurrence in next child is increased, if the cause of cerebral palsy in the first child was genetic, brain malformations or maternal drugs and toxins.

Risk Factors with Less Likelihood of Recurrence

If the first child has a strong history of an inciting event like complicated labor, abnormal presentations such as breech, asphyxia (where the baby did not cry immediately after birth and required help with breathing), untreated jaundice causing brain damage (kernicterus), and infections of the brain and meninges, the risk of recurrence of cerebral palsy in the next child is lower. Cerebral palsy attributable to causes happening later in childhood such as head trauma, refractory, or difficult to control seizures, and drowning will not affect the second child.

Precautions to be Taken

- Evaluation of the first child to establish a cause for cerebral palsy
- Routine antenatal care
- Care at birth
- Care after birth including management of prematurity and administering resuscitation as warranted.