GUIDELINES FOR PARENTS

Home Care of a Paralytic Child

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10 FAQs on HOME CARE OF A PARALYTIC CHILD

1. What is paresis? How does it affect the child?
2. What are the possible reasons causing paresis in a child?
3. Is it true that all the children with paresis need hospitalization? What are the alarming signs to consult my pediatrician or pediatric neurologist immediately?
4. My doctor advised neurorehabilitation for my kid with paresis. What is it? How does it work?
5. What are important do's and don'ts in taking care of paretic child at home?
6. How should I take care of nutrition in my child with paresis?
7. Can I continue all the vaccinations as per schedule in my child having paresis?
8. My child has recently developed paresis. Will his/her deficits be always permanent? Can he/she recover completely?
9. What are the possible immediate and long-term complications in a child suffering from paresis?
10. Does paresis affect the intelligence in my child? Can he/she attend mainstream schooling?

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Paresis or paralysis is the loss of voluntary movement of a part or all of the body. In simpler terms, the child loses muscle activity either in a part or the entire body. Medically, the term “plegia” is used. It is caused by numerous conditions which can be genetic or acquired later. Paresis can last transiently or remain persistent. The severity of affection may also be variable. Paralysis is termed as “localized” when only a part of the body such as the one part of the face or single limb is affected. Generalized paralysis is when muscle function of different body areas is lost (Fig. 1).

Effect of paresis on function varies greatly. There is limited range of movement at various joints due to muscle spasticity or dystonia. Some affected children can walk; others need assistance. The intelligence is variably affected from being near normal to having varying degrees of intellectual disability. Children with paresis can have problems with chewing and swallowing. Epilepsy (seizure disorder), vision, or hearing impairment may also be associated with the paresis.

**What is paresis? How does it affect the child?**

**Fig. 1:** Outline of various types of paresis affecting different body parts.
Muscle movement is controlled by signals from the brain, which are relayed through the spinal cord to the muscles via the nerves. Damage to this trigger or the relay pathways results in disruption of the signal, leading to muscle paresis.

Cerebral palsy is one type of paresis commonly seen in children. Cerebral palsy or “CP” is a broad term given to the several disorders ultimately leading to impairment of normal movement and posture in different parts of the body. It has many degrees of severity. This term is used when there is neurological damage to the developing brain during early developmental stages that prevents the brain from developing properly. However, not all paresis is CP and children may have generalized or localized paresis secondary to insults to the brain, spinal cord, nerves or the muscles.

Common Causes of Paresis in Children

- Genetic mutations disrupting nervous system development and causing brain malformations
- Perinatal asphyxia (difficulty in smooth initiation of breathing at birth)
- Infections: Intrauterine or acquired later causing meningitis, meningoencephalitis, myelitis
- Stroke and intracranial bleeds—perinatal and acquired causes
- Guillain-Barré syndrome (an acquired disease affecting multiple nerves of body)
- Head and spinal cord trauma
- Neoplasms (tumors)
If the child develops the paresis recently or acutely hospitalization is needed for child's stabilization and work-up for etiology, treatment, and further plan of management.

If the paresis of chronic origin (long duration) may not require hospitalization but still needs to see the specific specialist to determine the cause and prevention of recurrence.

Alarming Signs
Following are the alarming signs to consult your pediatrician immediately:
- Sudden weakness of part or whole body
- Convulsion
- Convulsion with altered sensorium
- Abnormal movements
- Behavioral problems
- Lethargy
- Refusal of feed
- Feeding difficulties
- Breathlessness (recurrent respiratory tract infection)
- Fever
- Increased paleness of body
- Pain
- Altered sleep pattern
- Constipation
- Progressive weakness (ascending or descending)
- Not passing urine and stools
Neurorehabilitation is a science dealing with restoration of maximum possible functional capacity in an individual with damage to the brain or the relay networks to the muscles. It works on principle of neuroplasticity, which is property of mainly developing brain by which brain learns/acquires specific ability/response to certain set of goal-oriented external stimuli. Neurorehabilitation is most effective when it is goal-oriented. Goal setting is the paramount and first task with parents/caregivers by the treating team of doctors.

Below is the list of various therapies used for neurorehabilitation (Fig. 2).

<table>
<thead>
<tr>
<th>Therapy</th>
<th>Purpose</th>
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<tbody>
<tr>
<td>Physiotherapy including aquatherapy/hippotherapy</td>
<td>To reduce the tightness of limbs, improve functions such as sitting, standing, and walking</td>
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<tr>
<td>Occupational therapy</td>
<td>Assist in activities of daily living</td>
</tr>
<tr>
<td>Speech/oromotor therapy</td>
<td>Assist in speaking, chewing, swallowing like functions</td>
</tr>
<tr>
<td>CIMT (constrained-induced movement therapy)</td>
<td>Very useful when one side of body is affected</td>
</tr>
<tr>
<td>Robotic device-assisted movement therapy</td>
<td>It is emerging advanced technique. Specific task and specific robotic applications are used to achieve predefined goals</td>
</tr>
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**Q4**

My doctor advised neurorehabilitation for my kid with paresis. What is it? How does it work?

**Fig. 2:** Correct methods of carrying paretic child.
What are important do’s and don’ts in taking care of paretic child at home?

Do’s

- **Priority to child care**: It is always essential to know about child’s health.
- **Therapy at home**: You as parent should take initiative to become therapists for your child. Learn the various techniques of therapy as much as you can and spending daily even 1–2 hours a day at home therapy can bring the encouraging results for your child.
- **Activity at home**: You should help your child to perform any activity to best of his/her ability.
- **Broaden their mind**: Help your child to expand their world.
- **Nutrition**: It is advisable to eat healthy and nutritious food.
- **Realization**: You should make them realize about their capabilities.
- **Parents support group**: They might lift your spirits on tough days.

Don’ts

- Do not ever feel guilty about double-checking references or visiting a center of care of your child.
- Do not rely too heavily on information from the Internet, word of mouth, or advertising.
- Do not forget to examine the center’s policies and procedures, inquire about activities, group size and curriculum, and get to know the people who will be in direct contact with your child everyday.
- **Do not guard your child**: You should prepare your child to face the difficult situations on their own rather than turning away, help them thrive through conflict, struggle, and consequences.
- Do not underestimate or neglect your child.
How should I take care of nutrition in my child with paresis?

These children have problems with their muscle tone, movement, and/or motor skills. Some may not coordinate feeding themselves or chew and swallow safely or successfully. Digestive problems such as gastroesophageal reflux and constipation can make eating uncomfortable and meal-time challenging.

- A diet and nutritional therapist can evaluate and plan an individualized diet taking into consideration all the points.
- Special emphasis to be given for micronutrients such as calcium, magnesium, iron, phosphorus, sulfur, vitamins A, B, C, and D along with adequate macronutrient such as protein and fat with rich fiber content to deal with constipation (Fig. 3).
- We advise you to keep a food diary, tracking child’s food and fluid intake, which can help a therapist understanding your child’s eating patterns and creating best diet plan to follow.
- In nutshell, the food should be easily digestible, palatable, adequate consistency and presentable homemade family food, enriched with fruits and vegetables along with dairy products. The idea is to offer food that they can eat with least frustration and distress.
- It is very important at every visit to discuss about nutritional status and plan to improve on it.

![Vitamins and Minerals](image)

**Fig. 3:** Pictorial overview of food enriched with various vitamins and minerals.
Vaccination rates among paretic children are significantly lower than normal children. It is mostly due to parental concerns that vaccination of their children may cause complications due to negative recommendations from ill-informed resources, resulting in a decline in vaccination.

These paretic children are more susceptible to infections as well as more likely to develop complications in diseases which are vaccine preventable.

But, at the same time, the immunogenicity or efficacy may be lower and risk of adverse events following vaccinations, especially live vaccinees may be higher, if they are significantly compromised. However, vaccination in them is perfectly safe than often perceived.

- There is no primary contraindication to any available vaccine in a paretic child. However, killed vaccines are preferred over live vaccines, if available. Some causes of paresis (e.g., nerve and muscle disorders) may need more frequent vaccines than the routine immunization schedule. It is useful to discuss the vaccination plan with your treating neurologist before taking the vaccine.
- “Routine Immunization Schedule” as guided by the Indian Academy of Pediatrics (IAP) should be followed.
- Even if your child was not immunized due to sickness or other relevant issues, your pediatrician will provide you a catch-up vaccination schedule to cover up all age-appropriate leftover vaccines.
If your child has developed paresis recently, then he/she requires hospitalization for stabilization, investigations for the cause of paresis and treatment according to the cause. His/her deficit may or may not be permanent. It totally depends upon the cause. If the causes are Bell’s palsy or stroke, then children may show complete recovery without treatment also or may have some deficit.

There is certain condition wherein the deficit is permanent, e.g., cerebral palsy. If injury to the brain or nerves leading to gliosis (scar) or volume loss, then there is no remedy for that and can lead into permanent paralysis. Infants are born with paralysis may not be permanent, depending on the cause, infant can recover most of their mobility. Children who are born with paralysis can get accustomed to their weakness and make adjustments to complete tasks with proper guidance. With good neurorehabilitation practice even, they can lead near normal life. Permanent damage to the brain gives rise to lifelong disability in given patient which can be very demanding to the parents physically, mentally, and economically. There can be financial constraint, but there are organizations and support groups which will help parents. Paralysis is a challenging condition for those who are affected and for their families but certainly not a hopeless condition at all. Though it may require team management, there are organizations and support group who can provide help in all aspect (financially, legally, and physically).
As already mentioned, acute onset of paresis usually needs hospitalization for optimal management. Immediate complications are usually seen in first 4 weeks of onset of paresis, mainly addressed during hospitalization by expert team of doctors, which include seizures/fits, altered sensorium/coma, brain edema, functional deficits in limbs or various other parts in body, various unwanted movements, loss of speech or vision, etc. In a long run by medications and also by natural capability, brain tries to heal thyself although it is not complete which leads to various degrees of residual functional deficits/disability.

Problems and Complications in a Child with Paralysis

| Weakness/Neuromotor impairments (causing major limitation to locomotion functions such as sitting/walking, etc.) | The involvement and distribution will depend upon the underlying disease causing paresis such as hemiparesis (weakness in one side of body), monoparesis (weakness of any one limb), paraparesis (weakness of both the lower limbs), quadriparesis (weakness of all four limbs). Affected limb(s) may become too tight (spastic) or too loose (flaccid) |
| Seizures | Child may have late-onset seizures after few months to years after brain injury |
| Sensory impairments | Deficits in vision/hearing or in perception of various other sensations |
| Speech impairment | Mostly in older child with paresis may have difficulty in speech in terms of problems in articulation, loss of rhythm, slow-word output, not able to pronounce certain sounds/letters, etc. |
| Bowel/bladder problems | May not able to indicate or feel either urine (bladder) or defecation (bowel) sensations |
| Bedsores | Mainly in quadriplegic child where she or he cannot move her/himself frequently may lead to bedsores/ulcers in dependent areas |
Does paresis affect the intelligence in my child? Can he/she attend mainstream schooling?

This depends upon the cause of paresis, area of brain damaged by it, and the age of the child. Certain causes of paresis do not affect the brain but damage the spinal cord, nerves or muscles. In such a scenario, the child’s intelligence is not affected. When insult happens in fetal life or in early infancy, then intelligence is usually lesser affected compared to the degree of brain damage due to the property of neuroplasticity of developing brain. While in certain scenarios when particular areas of brain (e.g., frontotemporal lobes) are damaged, the intelligence is most affected compared to damage to the other parts of brain.

Regardless of any cause of paresis, all the children with paresis should be given opportunity to mainstream schooling first. In very specific scenarios where IQ scores are very low or behavioral issues are profound, then special schooling should be considered. The decision of mainstream or special schooling must be individualized to each and every eligible child with paresis regardless of degree of deficits/disability.