

## Coping with Cerebral Palsy

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### Introduction

“COPING”, here it means coping by both parents and child with CP. Coping by parents means understanding and accepting the reality of their child’s needs. But coping by child means accepting his disability and adjusting to the rehabilitation for become functionally independent as much as possible. The ultimate result of the coping is which help the parents to choose the right interventions according to the child’s need. Also it helps the child to adjust, cooperate and overcome the difficulties during the interventions for a better quality of life.

### CP and Emotions

Every parent has their own expectations for his or her child. Everyone dream about what life will be there in the future of the child. Suddenly when they discover that the child has a serious disability that may affect the child’s normal life, parent response is grief and shock. Then they may then go through periods of denial, guilt, and anger. Final result is a great disappointment. These feelings are natural. Same time the child is also having emotional disturbances from the feeling that he or she is paralyzed, disabled or both. If the parent and child is coped with the situation, then it very easy for them to choose right way to the better future and that will invigorating their lives.

### Choosing the Right Treatment Plan

It is important to fully understand the treatment. Knowing the types of interventions, its durations, expenses, expected outcome, complications and professional services needed, as well as which institutes are available, will help you make the best result for the child and his family. This will guide the child and his family to a good result with fewer difficulties.

### Coping with the Treatment

Once the child and family choose SEMLARASS as the treatment, Children commonly experience post-operative pain following SEM-LARASS. The incidence of moderate to severe pain in children is influenced by factors such as the child’s medical condition and the type of procedure performed. Invasive and painful procedures are particularly distressing for children. Children often describe repeated invasive procedures as more distressing than any other aspect of illness or treatment. Unlike adults, infants and young children may not understand the reason for procedures and may not participate actively in providing consent. Infants and young children also may not understand the time limited nature of procedures.

Postoperative pain following SEMLARASS is managed by the child, his or her parent(s), nurses, physicians and other health care providers. Effective interaction is very important to effective pain management. Although preferences of the child and family deserve respect and careful consideration, the primary obligation of the health care providers is to ensure safe and competent care. Children attempt to prevent or alleviate pain whether or not health care providers do so.

1.	Holding an adult's hand
2.	Holding a stuffed toy or favourite blanket
3.	Asking questions
4.	Using distraction
5.	Sleeping, resting, relaxing
6.	Changing positions

**Table 1:** *The child's coping response to pain.*

### Reduce Anxiety

Parents are often anxious and worried about their child's future. The anxious parents need reassurance from the medical professionals with regards to the course of treatment of their child and the prognosis as they would like to see their child improving functionally. Any changes in child's behavior like becoming aggressive due to pain, fussing while eating, constant complaint about having pain, decreased level of activity, changes in appearance, becoming silent, withdrawal, etc. causes more worry for the caregivers. The care givers tend to compare the activeness of the child prior to surgery and worry about decreased level of activeness in the child after surgery. This is especially true when there is slow or delayed improvement in the child. So effectively communicate with the rehabilitation team for alleviating the doubts, confusion and anxiety.

**Find out the usual causes of burnout** in caregivers while attending to their ward and find solution. Common causes are: 1) Financial burden: hospital expenses, post-operative treatment expenses, 2) Hospitalisation of their child, 3) Home environment: attending to the needs of the other family members, lack of time to attend to their own personal needs, being away from the family for the treatment of the child, feeling of guilt if there is perceived neglect of the child, lack of support and help from the other family members, time constraints of working parents, misunderstanding between the parents, 4) Different roles played by caretakers – as a parent, as nurse, as therapist, 5) Other stress at home or the work place and 6) Stress of prolonged treatment. All these cause a lot of frustration to the caregivers and in turn can affect the child's progress.

**Get enough education and training:** Unlike many other types of paediatric surgery SEMLARASS requires more involved post-operative care and home management of the child. Effective rehabilitation of the child requires expert pain management. Rehabilitation depends upon many aspects and it takes some time for the child to cope with activities of daily living. Hence it is necessary to give education and training for the parents regarding pre and post-operative treatment aspects.

Children experience a lot of distress due to pain and caregivers should help and support them to cope with the pain. The children will need sympathy and extra care during this time as they are very sensitive to criticism. Parents need to know and understand what their child can do and accept the limitations of the child. Gentle handling of the child, taking care of the physical needs and a sympathetic behaviour towards the child are most important. Functional recovery following SEMLARASS is not dramatic and rehabilitation should be viewed as is a long term process.

Caregivers need to have patience and encourage the child to undergo the treatment. As rehabilitation is slow and tedious, the caregivers need to be counseled with regard to the expected duration of recovery and the expenses involved. The caregivers should know that frequent expressions of irritability, frustration or anxiety, reflected in their body language or gestures can become an impediment to the child's recovery.

**Prepare well prior to the surgery:** Visit the hospital to acquaint a child with what will happen during his or her hospital stay. Find out what is causing a child to be anxious about visiting the hospital, and talk about the fears. Some of the issues may include sharing a room

with another child, being alone at the hospital, getting medication or injections and going to sleep with the surgery. Teach a child how to relax through special breathing and relaxation techniques. Your physiotherapist should do this well in advance of the surgery. During the hospital stay, instead of just reassuring the child that they will feel better soon, distract the child with video games, movies, music or television. For younger children the talking story books are good distractions. Parents can use these techniques during medical procedures and while children are recovering.

Also explain and understand the child about benefits from the surgery and rehabilitation rather than burdens.

**Other tips for caregivers:** 1) Ensure that the child gets freshly prepared and nutritious food and lots of fluids. 2) He child must be in a relaxed frame of mind before doing the home exercises. 3) Adhere to the scheduled follow up appointment with the surgeon, to help parents understand the current status of the child. 4) Any abrupt changes in the child's behavior should be brought into the notice of the surgeon or any other rehabilitation team member. 5) Positive reinforcement would give immense support to the child. 6) Parents need to understand the limitations of child. 7) Make the child understand the importance of post-operative rehabilitation. 8) Positive reinforcement, motivation, and cajoling the child when required. 9) Diversion activities – like playing with the child, talking about aspects that interest the child, relaxation exercises like controlled breathing, imagery, drawing, painting, singing and other activities of interest will relax the child. 10) Building up the child's self-confidence and helping them develop an interest in the physical therapy. 11) Understand and respect the needs of the child. 12) Give moral and psychological support to the child. 13) Learn to identify when the child is manipulating them, perhaps to escape from physical therapy and other rehabilitations. 14) Caregivers should take care of their emotional and personal needs while attending to their wards. 15) In case of any doubt, consult the rehabilitation team member 16) Consult the child psychologist or psychiatrist in managing the behavioural aspects of the child. 17) Caregivers can take turns in looking after the child. 18) Encourage the child to express the pain rather than hide it.

### Financial Concern

The most important thing that all the parents must do for their child is to find out and ensure for a good financial support from Govt., NGO's, relatives and/or insurances for completing the entire rehabilitation prior to the surgery. All parents could begin focusing on the child's and family's happiness instead of looming medical bills. Financial constrain during the rehabilitation will negatively affect the child's overall functional outcome.

### Parents Support Group

Parents support group is very much important with hundreds of parents who know exactly what happened to the child, barriers and solutions to overcome it in every step of the way. This will help each parent in guidance, in formations, support and an emotional support when each time the child reaches a milestone, each time the parents feel depressed or disappointed.

### Conclusion

Rehabilitation requires a broad range of clinical skills, not only medical or technical, but also psychological and social to cope up with the patient and parents to the situation. Medical professionals involved in treating children after SEMLARASS should be sensitive and skilled while handling their clients to rise to the occasion. Equal importance should be given to rehabilitating the client, and educating the care takers about the treatment aspects, helping them manage their wards, respecting their feeling and help them cope with an exceptionally stressful event (i.e., the surgery and its aftermath).

### Bibliography

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