

# Parent Guide Book For Cerebral Palsy

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# **Parent Guide for Cerebral Palsy**



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# Parent Guide for Cerebral Palsy

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This book is basically a compilation of information / literature on the available on the topic, from various sources (which have been acknowledged duly). However, this is by no means an exhaustive resource, since the field is evolving at a very rapid pace. Every effort is made to ensure accuracy of material, but the publisher, printer and author will not be held responsible for any inadvertent error(s).

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## Preface

There have been times in human civilization when quantum leaps have occurred in technology that has had a direct impact on the quality of human lives. This time has now come for children suffering from cerebral palsy. For decades these children have suffered from physical limitations and cognitive impairments resulting in their inability to integrate into the routine of society. The last two decades have however seen a major shift in the overall management of cerebral palsy. Comprehensive rehabilitation, availability of newer drugs for spasticity and epilepsy, newer surgical techniques in orthopedics and neurosurgery, neuromodulation and stem cell therapy have completely transformed the current management of cerebral palsy. We have shifted from hopelessness to hope and from lack of options to the availability of multiple options in all aspects of cerebral palsy care.

Despite all the recent advances in the medical world, the major responsibility of managing these patients is still with parents. We believe that knowledgeable, well informed and empowered parents can make all the difference between a dependent CP child and a self dependent one. The availability of internet has made a whole lot of information available to parents which can sometimes be more confusing than enlightening. It is for this purpose, we decided to write this book which covers in a simple easy to understand language all the key issues that go into efficient management of a cerebral palsy child.

Our country has played a pioneering role in the overall evolution of treatment methods for cerebral palsy. The pioneering work on the management of spasticity from Hyderabad, pediatric orthopedic surgery from Mumbai and the newly developed work on stem cell therapy also from Mumbai are examples of the leadership roles our country has played in this field. Our rehabilitation specialists are among the best in the world since they combine a diligent professional competency with human warmth and caring. The result of this combination of the availability of newer treatment methods combined with holistic rehabilitation has resulted in patients from overseas now choosing to come to India to avail of the treatment opportunities here. This is a matter of national pride. However, there is still a lot more to be done. Children from rural areas do not have access to rehabilitation; our urban schools are often not equipped for inclusive education, our public hospitals are not geared up for some of the more advanced treatments that CP children can benefit from, wheelchair access is limited in most public areas and public awareness and government encouragement for families of CP children is limited. We, therefore have a lot of work to do. We hope that this book is one small step in this direction in the world of cerebral palsy.

I conclude with the words of Robert Frost.

*"The woods are lovely, dark and deep, But I have promises to keep,  
And miles to go before I sleep, And miles to go before I sleep"*

**– Dr. Alok Sharma**



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*“To succeed in your mission, you must have single-minded devotion to your Goal”*

*“When we tackle obstacles, we find hidden reserves of Courage and resilience we Did not know we had .and It is only when we are Realize that these resources Were always there within us.We only need to find them and move on with our lives.”*

*“We should not give up and we should not allow the problem to defeat us”*

*“My message, especially to young people is to have Courage to think differently, courage to invent, to travel the unexplored path, courage to discover the impossible and to conquer the problems and succeed. These are great qualities that they must work towards. This is my message to young people”*

**– Dr. A.P.J. Abdul Kalam**

## India's Pioneering Role in the Field of Cerebral Palsy

Cerebral palsy is one of the most difficult to treat pediatric neurological conditions and it requires a multidisciplinary team approach. More importantly the treatment of cerebral palsy is dependent on dedicated and devoted personnel committed to the cause and willing to work patiently and with perseverance over several years to help improve functionality and capability of these children. India has been blessed with some outstanding individuals and exceptional associations and organizations that have worked for the cause of CP children. We highlight some of these organizations and individuals. This list is not exhaustive and is only representative of the many doctors, therapists, NGOs, associations, institutes and hospitals that consistently work day after day to make life a little bit easier for the CP children and their families.

### Indian Academy of Cerebral Palsy (IACP)

The Indian academy of Cerebral Palsy, a national body, constitutes the pioneers from across the country working actively in the field of cerebral palsy. All of them together share the same vision of contributing towards the well being of the cerebral palsy patients and their families. The main aim of the IACP was to bring together health & rehabilitation professionals, organizations and parents of these patients to create awareness. They have achieved this to a great extent through various mediums such as newsletters, scientific articles, awareness programs and other activities.

The first founder president of IACP was Late Dr. Perin K Mulla Feroze. However, its formation was made possible mainly due to the efforts of Dr. Anirudh K Purohit. The IACP was inaugurated officially at Mumbai during the Asia Pacific childhood Disability Update held in December 2005. Dr.M.S.Mahadevaiah, Developmental pediatrician, Spastic society, Karnataka, was named the first president of the organization.



The 1st annual conference of IACP was held at Hyderabad in November 2006 under the guidance of Dr. Anirudh K Purohit, the General Secretary. The 2<sup>nd</sup> annual conference was held at Bangalore in November 2007 under guidance of the President Dr.M S Mahadevaiah & Mrs.Rukmini Krishnaswamy of Spastic Society of Karnataka. The 3<sup>rd</sup> annual conference was held at Nagpur in collaboration with NKP Salve Institute of Medical Sciences in November 2008 under the leadership of Dr.Vittal Rao Dange of NKPSIMS and Dr.G.Shashikala, Associate. General Secretary of IACP. During this conference, Dr.Ashok N Johari was unanimously elected as President.

### IACP pioneers

1. **Dr. P K Mullaferoze:** Late Dr. Perin K Mulla Feroze, was a dynamic lady orthopedic surgeon who spent her whole life running



the cerebral palsy wing of children's orthopedic hospital in Haji Ali, Mumbai which was the first multidisciplinary service provider for children with cerebral palsy in India. She became the founding president of the Indian Academy of Cerebral Palsy (IACP). Dr. Mulla Feroze often described herself as a "*battle scarred veteran in the fight against cerebral palsy.*"

2. **Dr. M. S. Mahadevaiah :** Dr. M. S. Mahadevaiah is a developmental pediatrician, and was the First president of Spastic society, Karnataka,. He later became the president of IACP and officially inaugurated The Indian Academy of cerebral palsy in 2005. He is the pioneer to have started teaching developmental pediatrics at Bangalore after returning from USA.
3. **Dr. Anirudh K. Purohit:** Dr. A. K. Purohit is the neurosurgeon, under whose guidance the IACP was successfully funded. He has received around six awards for his work in his field. He has been honoured with Vaidya Ratna Upadhi by Sree Sree Jagadguru Shankaracharya. Dr. Purohit is a member of twelve international and national medical organizations and has published seventy articles in medical journals, general magazines and newspapers and contributed chapters in 6 medical books. He is the chief editor of the Indian Journal of Cerebral Palsy and has also published a guide on Cerebral Palsy in Hindi. His special interests are management of spasticity and he has developed a new technique known as *Selective Motor Fasciculotomy* and has the largest series to his credit.
 
4. **Dr. Mithu Alur:** Dr. Mithu Alur is the founder chairperson of The Spastic Society of India (ADAPT - Able Disable All People Together). She is also the member of the Central Advisory Board on Education (CABE). She has been appointed Member, Executive Committee of the National Mission of the Sarva Shiksha Abhiyan (SSA). She is an educator, disability rights activist, researcher, writer and published author on issues concerning people with disability in India. She monitors the implementation of the services of the Spastic Society of India through the Heads of Departments and Directors who report directly to her. Dr. Alur is also the chief fundraiser for the organization through national and international joint projects.
 
5. **Dr. A. K. Johri:** Dr. Ashok Johari is a renowned Pediatric Orthopedic surgeon. He is a teacher and surgeon par excel having gathered a national and international reputation. He holds professorial position at Grant Medical College and is a visiting surgeon to many other hospitals. He spear headed the Pediatric Orthopedic movement in the country and is now the President of the Pediatric Orthopedic Society of India (POSI) and the founder Vice-President of the Indian Academy of Cerebral Palsy (IACP). He is associated with various philanthropic activities and runs an annual Pediatric Orthopedic camp in Mumbai for 4 days wherein the patients are treated free of cost. He has conducted many
 

workshops on pediatric orthopedics, spinal deformities, cerebral palsy, spastic management, and use of botulinum and surgery in Cerebral Palsy. He is also involved in research and innovations in treatment. He is a part of many international editorial boards and is the Editor of the prestigious international journal – The Journal of Pediatric Orthopedics (B).

## **Spastic Society of India**

The Spastic Society of India, now renamed as ADAPT – Able Disabled All People Together, is India's leading non-profit, non government organization started in 1972 by Dr. Mrs. Mithu Alur to provide education and treatment assistance for patients with cerebral palsy. It was started in Mumbai and actress Nargis Dutt became its first patron. The first special school for Cerebral Palsy was set up in 1973. It was followed rapidly by several schools being opened in Kolkata, Bangalore, Chennai and New Delhi. This was followed by forming Spastics Society of Northern India in 1977, Spastics Society of Karnataka in 1980, Spastics Society of Tamil Nadu in 1980 and Spastics Society of India Vidyasagar in 1985.

Spastics Society of India, Mumbai, as a catalyst, started training of teachers and therapists and skills development. Similarly, the Spastics Societies located in the Eastern, Southern and Northern regions have been very active in training, in providing technical support and networking. The Spastics Society of Karnataka has established facilities for early diagnosis, appropriate intervention, special education, with a National Open School facility. It also runs a vocational polytechnic and ongoing training programme in all these areas. The community based programmes, both rural and urban, run by the Spastics Society of Karnataka, have a wide and effective reach. In 1999, it also established the 'National Resource Centre for Inclusion (NRCI), in Mumbai, to include disabled children from special schools into normal schools.



# **SECTION A:**

## **Understanding Cerebral Palsy**



# 1. What is Cerebral Palsy?

Cerebral palsy is a movement disorder causing inability to perform movements due to lack of muscle strength, muscle co-ordination or excessive tightness of the muscles. This is because of the brain damage and not because of primary muscle damage. The damage to the brain causes abnormal or absent signals reaching the muscles, which causes weakness or stiffness of the muscles and abnormal movements. *Cerebral* means pertaining to the brain and *palsy* means paralysis. It is caused due to poor development or damage to the brain during gestation, at birth or after birth up to 1 year. Although, primarily a movement disorder; it may also lead to impairments in understanding and cognition, learning, intellect, behavior, communication, speech, sensations, perception, hearing and vision; depending upon the areas of the brain damaged.

Cerebral palsy is permanent and affects the children for life. The damage to the brain is neither progressive nor reversible; meaning the damaged part will not get worse nor will it repair completely. The symptoms however may worsen or get better depending upon how the child is taken care of. It is therefore very important to understand what are the symptoms and associated problems with cerebral palsy and how to best manage these so that the difficulties experienced by the child do not increase.

Although the brain is damaged in every child with cerebral palsy, its effects are very different in each one of them. No two children with cerebral palsy are the same; it affects every child differently. The impairments experienced by these children range from normal intelligence but mild difficulty in walking or balancing to severe cognitive and physical debility leading to complete dependence for all activities of life. Every child with cerebral palsy needs tailor made management program that changes as the child grows.

The earlier cerebral palsy is identified and management program is started, the better are the chances of recovery with lesser associated problems. All the children with cerebral palsy benefit from seeking early intervention and guidance. Their needs for learning may be different and must be taken into consideration so that they can develop their abilities and overcome their disabilities.

Cerebral palsy is a leading cause of childhood disabilities in India. 3 in every 1000 births are diagnosed with cerebral palsy. Most of the children with cerebral palsy have severe disabilities. The parents may find themselves hopeless and helpless after



finding out the prognosis of the condition. Cerebral palsy not only affects the child but the whole family. It is important that the whole family participates in taking care of the child as well as each other. Cerebral palsy requires a family centered care and not just a patient centered care. The primary focus of this book is creating awareness and guide parents and caretakers of children with cerebral palsy. Understanding about cerebral palsy by the parents and caregivers will empower them to give appropriate and best care to their child. Knowing the underlying causes or risk factors may help them to prevent further complications.

In the era of internet there is vast information available about cerebral palsy and it could be quite overwhelming for the parents and caretakers to read this information. We understand that parents have many concerns, questions, and doubts, related to their child's health and limited ability. The aim of this book is to answer their questions, to put together the important information they need to know about cerebral palsy in one book. This book also attempts to provide hope for those associated with cerebral palsy by introducing them to the whole new world of advanced medical treatments like stem cell therapy which can potentially address the root cause of cerebral palsy and also the existing medical, surgical and rehabilitative managements that can significantly improve the quality of life and independence of children with cerebral palsy. Through this book we hope to provide you with information about what you should do as a parent to help your child achieve to the best of his abilities.

## 2. Types

There are various types of cerebral palsy. The management of children with cerebral palsy depends greatly upon the type of cerebral palsy. The types of cerebral palsy are based on the kind of movement abnormality and the areas of the body affected.

### Types of Cerebral Palsy based on the body parts impaired

Different parts of the brain are responsible for controlling the movements of different body parts. Depending upon the kind of damage or developmental anomaly different body parts get affected. Figure shows which parts of the brain are responsible for which body part.

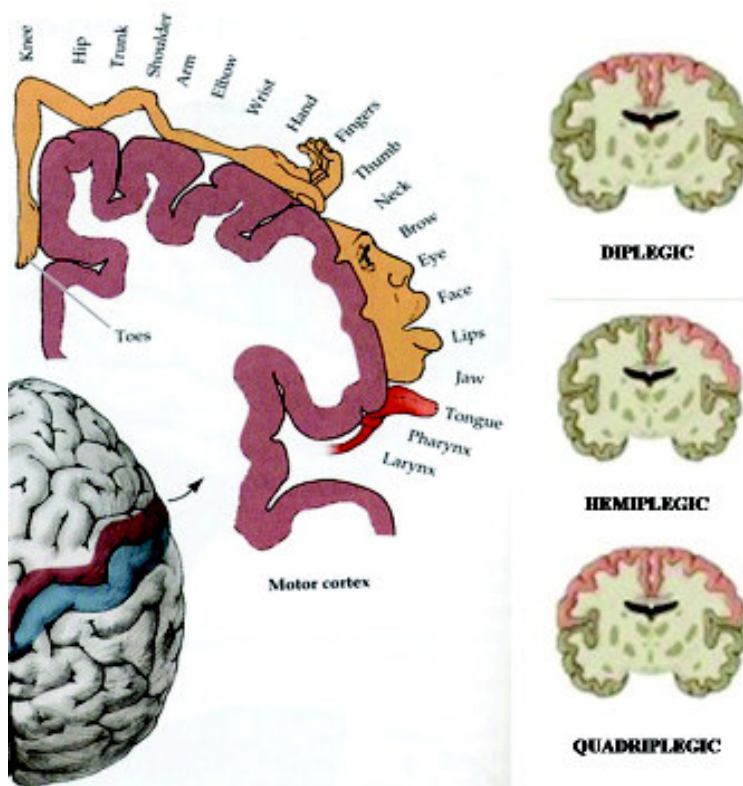


Figure 1: Areas of brain responsible for impairment of different parts of the body

Based on how many of the limbs are impaired cerebral palsy is classified into 5 different types.

### 1. Quadriplegic(All four limbs affected)

This is the most common type of cerebral palsy observed in India. This occurs because of severe damage to the brain on either sides, caused by insufficient oxygen supply at or after birth. Both the arms and legs show impaired or lack of movements and abnormal muscle tension. Children have poor voluntary control of the arms and legs. They may also have difficulty in sucking, swallowing and frequent respiratory infections due to aspiration. Cognitive deficits are also associated with this type and children may have very poor learning abilities, understanding, memory and intellect.

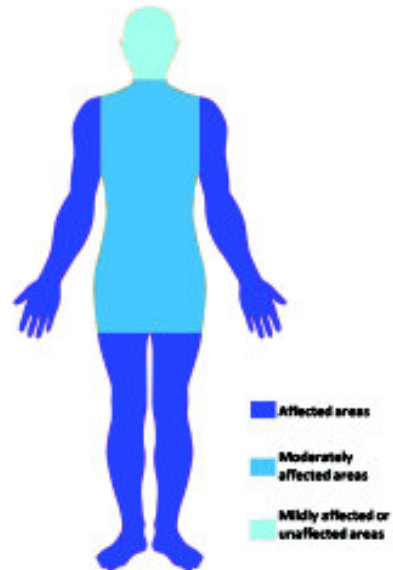


Figure 2: Areas affected in Quadriplegic CP

### 2. Diplegic(Both the legs affected)

Diplegic type of cerebral palsy is often seen in children that are born prematurely or have low birth weight. It is caused due to lack of blood supply to the brain during development or at birth. Brain damage extends to both the sides. In this condition, legs are more severely impaired than the arms. In mild cases increase tension in the calf muscles leads to inability to lift the foot up and children exhibit toe walking. Whereas in severe cases, there is flexion of the hips, knees and to a lesser extent elbows. When the child is held vertically, rigidity of lower limbs is most evident and adductor spasm of the lower extremities causes scissoring of the legs. Children may also exhibit associated visual impairments.

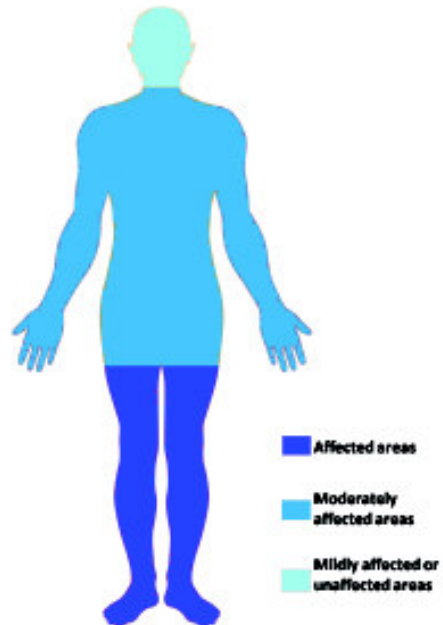


Figure 3: Areas affected in Diplegic CP

### 3. Hemiplegic(Arm and leg on one side affected)

In this type of cerebral palsy arm and leg on any one side are impaired. Most often arm is affected more severely than the lower extremities. Most commonly affected movements are moving the wrist upwards and turning the palm upwards with fine movements of thumb. In the lower limb, foot movements of moving the foot upwards and outwards are affected most commonly. There is increased tension in the muscles causing flexion at the elbow, wrist and knees and inward turning foot. These children may also experience some changes in the sensations, vision and paralysis of facial muscles.

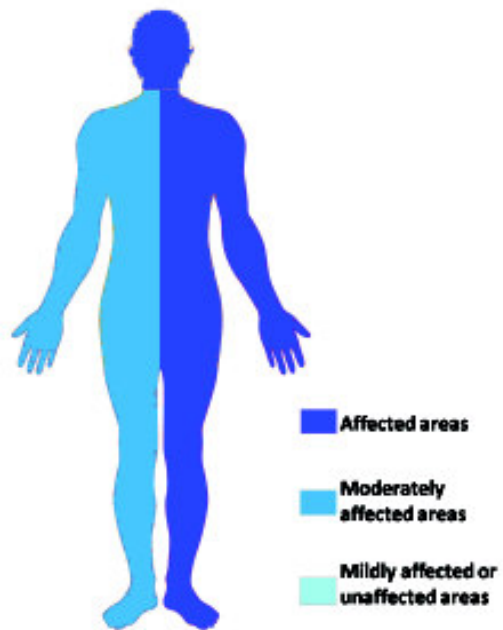


Figure 4: Areas affected in Hemiplegic CP

### 4. Monoplegic(Any one limb affected)

This is a rare type of cerebral palsy resulting due to very minimal damage to the brain areas, where only one of the arms or legs are impaired

### 5. Triplegic(Both the legs and any one arm affected)

This is also a very rare type it mainly occurs when the damage to one side of the brain is more than the other; causing overlap of symptoms of hemiplegia and diplegia. This type shows that primarily both the legs are impaired but only one of the arms are impaired significantly.

In India, majority of the children exhibit spastic quadriplegic type of cerebral palsy followed by spastic diplegic and hemiplegic cerebral palsy. Monoplegic and Triplegic types are observed very rarely.

## Types of cerebral palsy based on the area of the brain damaged

Different areas of the brain not only control different body parts but also different aspects of movement. Some areas are responsible for causing appropriate tension in the muscles so that we can move a body part, whereas some are responsible for balancing the tension in different muscles groups for timely smooth movement. Some areas are responsible for co-ordination of the body movements with visual, auditory

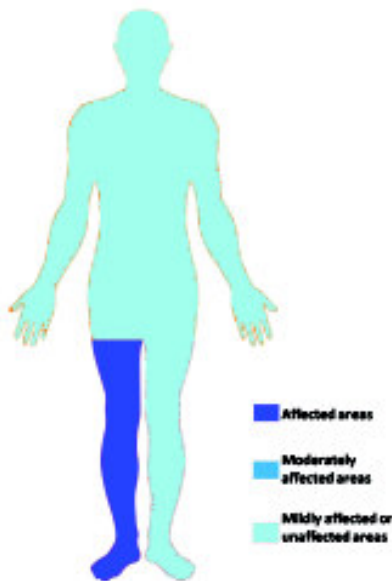


Figure 5: Areas affected in Monoplegic CP

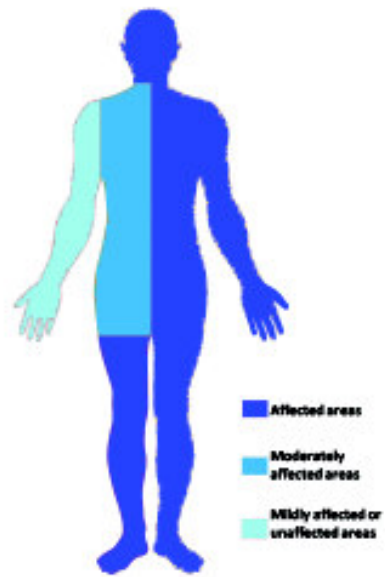


Figure 6: Areas affected in Triplegic CP

and other sensory cues. Figure shows different parts responsible for these functions. Damage to these parts results in variations in the muscle function and movements, based on which cerebral palsy is divided into 3 types.

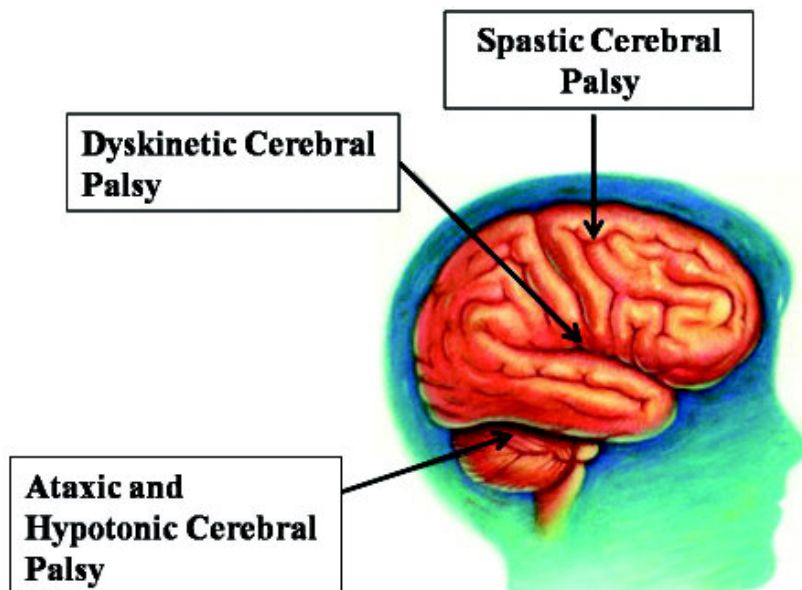


Figure 7: Areas of brain damaged in different types of CP

## 1. Spastic (Increased stiffness in the muscles)

Spastic cerebral palsy occurs due to the damage to the cerebral cortex of the brain. This is the area responsible for bringing about movements in the body by altering the tension in various muscles. The word spasticity relates to increased tension in the muscles. The muscles need a certain amount of tension to work efficiently. If this tension increases then it causes the parts of the body to be rigid and stiff and difficult to move. Children that exhibit such stiffness in their body parts are categorized into spastic cerebral palsy. The tension of the muscles may vary depending on various factors. The tension may increase when the child is upset. Certain postures and head positions may increase the tension in certain muscles of the body. This increased tension causes awkward, lazy and laborious movements. Children therefore tend to keep the arms and legs in fixed positions which can cause permanent tightness of the muscles and restriction of the joint movement.

## 2. Dyskinetic (Abnormal movements of the body)

Dyskinetic cerebral palsy occurs when, basal ganglia, the part of the brain responsible for controlling the voluntary movements is damaged. Basal ganglia is responsible for balancing the activity of the brain to balance the tension in various muscle groups. This leads to various abnormal, uncontrollable movements in the body.

These abnormal movements are of different type based on the quality of the movement and tension in the muscles.

### *Dystonic (fluctuating muscle tension)*

The tone in the muscles in this type of cerebral palsy is varying and the movements caused could be sluggish and wriggly or jumpy and nervous movements. These movements are generally observed in the big joints like shoulder, elbows, hips, knees and trunk. Most often the abnormal movements are seen with the voluntary movements but sometimes they can be observed even at rest. Child usually finds it difficult to stand up and walk because of poor voluntary control. Whenever the child starts to move his body parts, they may move too fast or too far and uncontrollably. The tension in the muscles also varies when the movements are performed. The postures as explained above in the spastic type may come and go. Unlike spasticity it may not always be evident on passive examination.

### *Athetoid (Jerky uncontrollable movements)*

In this type the movements are very jerky and uncontrollable associated with voluntary movements. These are sudden quick movements of the child's feet, arms, hands and face muscles. The child's balance may be poor and he falls over easily. Most children with athetosis have normal intelligence, but if the muscles

needed for speech are affected, it may be hard for them to communicate their thoughts and needs.

### **3. Ataxic (Clumsy movements and poor balance)**

This type of cerebral palsy is caused due to damage to the Cerebellum. Cerebellum is the part of the brain that is required for co-ordination of the movements and maintaining balance. Damage to this part of the brain results in ataxia, characterized by in-coordinated movements and loss of balance. The child may find it difficult to perform fine activities with the hands and fingers, when attempting to touch a particular object they may under or over reach it, their hands and legs may shake uncontrollably when attempting to perform a movement, they may not be able to perform rapid alternating movements with their hands and legs, there is general slowness of movements and most importantly they may lose balance often and walk in a zig-zag pattern.

### **4. Hypotonic (Floppy muscles)**

Hypotonic cerebral palsy also occurs when there is injury to the Cerebellum. Hypotonia is opposite of spasticity. In spasticity there is increased tension in the muscles but in hypotonia there is reduced tension in the muscles. The muscles are flail and the child may find it difficult to achieve and hold a posture. The movements are sluggish. Hypotonia may mimic as muscle weakness as the child may not be able to perform voluntary movements. The children are usually floppy with exaggerated joint movements. They may achieve sitting, standing and walking very late and may not be able to perform these without support. If they achieve sitting they are always with drooping shoulders and sagging posture. Although these children are unlikely to develop deformities of extremities like in spasticity; they may develop deviated spine and deformities of spine.

### **5. Mixed**

Mixed cerebral palsy is when the symptoms of two or more of the above types co-exist. This form of CP is rarely observed and is difficult to diagnose. The management can also be complicated.

Parents and caregivers should be aware about the various types of cerebral palsy because the management will vary accordingly. Some types may require surgical correction of the associated complications. Early identification of the types will also help in early detection of the possible complications and their prevention.

## 3. Causes

Various causes have been identified for cerebral palsy which are divided into factors that affect during pregnancy, factors at birth and immediately after birth and factors after the child is born up to one year. It is important to understand that there are some causes of cerebral palsy; whereas others are only risk factors. The meaning of risk factors is that the children who exhibit those factors are only at the risk of cerebral palsy and not all of them will have cerebral palsy. Having a risk factor does not mean that the child will have cerebral palsy. Cerebral palsy may be the result of combination of these and rarely because of only one factor. There are some risk factors that are associated with mother and some associated with the child. Following is the brief overview of the causes and risk factors for cerebral palsy.

### 1. Prenatal (Before birth)

#### Causes

*Abnormal development of brain and brain malformations* – These are also known as congenital mal-formations i.e. abnormal brain structures present from birth, the reason for these abnormalities is not always known.

Some examples are,

1. *Schizencephaly* – where parts of brain are underdeveloped causing presence of slits or clefts.
2. *Cerebral dysgenesis* – abnormal brain development.
3. *Chromosomal abnormalities* – These are abnormalities caused by genetic defects and can be inherited from one generation to the other. There are many types of genetic defects that are associated with cerebral palsy.

#### Risk Factors

1. *Infection to the mother* – Any infection in the mother may increase chemicals that are required to fight infection. These chemicals may sometime pass through the circulation and enter the fetal circulation (child's blood supply in the womb) causing injury to the fetal brain. In simple terms it causes swelling of the fetal brain that may hamper the growth of the brain. Certain infections known to



cause brain damage and cerebral palsy are Rubella (German measles), Cytomegalovirus (Mild viral infection) and Toxoplasmosis (a usually mild parasitic infection). Infection to the, reproductive tract, urinary tract and placental membrane ( a layer of tissue that separates mother's blood from the child's to protect the child from any infections or toxic chemicals in mother's blood ) increase the risk of cerebral palsy.

2. *Intrauterine infection* - An infection acquired by the child while in the womb. This could be transmitted to the child through blood or sometime if there is injury and disruption of the protective layers in the womb leading to bacterial infection.
3. *Medication* – If the mother is suffering from a condition that needs medical treatment. Some of the medications like Phenytoin, that is used to treat epilepsy, may lead to abnormal development of the fetus. Sometimes drugs that are available without prescription can also increase the risk and therefore pregnant women should always consult a physician before taking medicines.
4. *Teratogens*– Teratogens are the substances that may cause birth defects in a fetus. Consumption of some chemicals like alcohol, nicotine (cigarettes, tobacco consumption), amphetamines, heroin, cocaine puts the child into a high risk of abnormal brain and body development that may lead to cerebral palsy.
5. *Injury to fetal brain* – Injury to fetal brain due to physical trauma or trauma caused by infections and toxic chemicals increases the risk for cerebral palsy.
  - **Periventricular leukomalacia (PVL)** is injury to the white matter in the brain. White matter in the brain is responsible for carrying nerve signals. Injury to this can result in motor and intellectual deficits.
  - **Hypoxic-Ischemic Encephalopathy (HIE)** is another type injury to the brain that is caused by lack of blood and/ oxygen supply. This could be due to sudden drop in maternal blood pressure, blood containing less oxygen due to poorly functioning lungs, heart complications, bleeding in the uterus, rupture of the uterus and rupture of the placenta.
  - **Intraventricular Hemorrhage (IVH)** is bleeding inside the cavities of the brain. This can be caused due to clots in placental blood, poorly formed and weak blood vessels, abnormal blood clotting, high blood pressure of the mother, maternal infection, and physical injury to the brain

## 2. Labor and delivery (At birth)

### Risk factors

1. *Prematurity* – If the child is born before completing the pregnancy period the risk for cerebral palsy increases. Children born before 32 weeks of gestation have a greater risk of developing cerebral palsy.
2. *Low birth weight* - Children weighing less than 2500 gms have a higher risk of developing cerebral palsy.

3. *Delayed cry*- Cry of the baby signifies opening of the lungs which are non-functional in mother's womb, as the baby is suspended in the fluid. If the baby does not cry immediately it may mean that the lungs are not functioning appropriately and the child is unable to breathe. This leads to lack of oxygen supply to the brain and increased risk of cerebral palsy.
4. *Injury at birth* – Fetal brain can be injured due to physical trauma caused at birth due to disproportion of the birth canal of the mother and head circumference of the baby, use of devices for delivery, use of suction to assist in delivery, rupture of uterus and breech presentation (baby is in the inverted position in the uterus)
5. *Multiple births* - Twins, triplets, and other multiple births have a higher risk for CP. Multiple births are also sometimes associated with premature birth and low birth weight which are known risk factors for cerebral palsy. If during the delivery one of the infant dies then the risk of cerebral palsy for the surviving infant increases even more.
6. *Infection* – Infection to the fetus due to rupture of placenta, uterine walls, bleeding in the vagina, infection of the umbilical cord and infection spreading through blood of the mother (septicemia) may result in brain damage and hence cerebral palsy.
7. *Toxemia* – Toxemia is caused when there is increased toxin released in the blood and death of the tissues due to infection. In the womb mother's blood is filtered through the placental membrane; but at birth the child may come in contact with these toxic chemicals that may damage the brain.

### 3. Perinatal (Immediately after birth)

#### Risk factors

1. *Asphyxia (lack of oxygen)* – Birth asphyxia refers to lack of oxygen supply to the infant brain. This may be caused due to physical trauma or other factors like poor oxygenation of mother's blood due to difficulty in breathing or any respiratory or cardiac disorders; low blood pressure, inadequate relaxation of the uterus, rupture of the placenta etc. In response to this the heart rate of the baby may drop, the skin turns pale to blue and baby seems very weak and flail.
2. *Pathological Jaundice* – Jaundice is the condition identified as increased levels of bilirubin in blood. Bilirubin is an enzyme secreted by Liver. Increased level of bilirubin is suggestive of impaired liver function. If these levels are not controlled it can become toxic to healthy tissue and cause cell death. In many infants increased levels of bilirubin in the blood causing damage to the brain cells is responsible for cerebral palsy.
3. *Epilepsy* – Epilepsy is a neurological disorder characterized by presence of seizures known in common terms as fits. A seizure may cause irreversible brain damage. Epilepsy is very often associated with cerebral palsy. The causes, symptoms and management of Epilepsy has been explained in detail in Section B.

4. *Hydrocephalus* - Hydrocephalus is a condition where there is excessive accumulation of fluid in the ventricles (cavities) of brain. This excessive accumulation can exert additional pressure on the surrounding brain tissue and may lead to reduce blood and oxygen supply to brain. The causes, symptoms and management of Hydrocephalus is explained in detail in Section B.

#### **4. Early Childhood**

##### **Risk Factors**

1. *Traumatic Brain Injury (TBI)* – Injury to the head or brain of a child due to physical trauma (falls, accidents etc.) may result in cerebral palsy. The brain development continues after the child is born and the injury during this phase of development can lead to various neurological impairments causing cerebral palsy.
2. *Infections* – Infection to the brain of the infant like meningitis (infection of the coverings of the brain) and encephalitis (infection of the brain tissue) may result in irreversible damage and cerebral palsy.
3. *Epilepsy* – Seizures that occur not only immediately post birth but within first year of life that cannot be controlled by medication may lead to severe irreversible brain damage leading to cerebral palsy.

#### **5. No obvious cause**

In a small percentage of children with cerebral palsy there are no obvious causes identified.

As described above there are numerous causes and sometimes it may be difficult to pinpoint the exact cause. It may be helpful to know the cause so that proper treatment protocol can be planned. This also aids in prognosis of the condition.

## 4. Clinical Signs and Symptoms

Cerebral palsy is a disorder with a diverse clinical picture the signs and symptoms vary depending on the type and severity of the brain damage. The signs of cerebral palsy are the effects that can be observed and tested by the clinician. These signs are observed right from the early childhood and infancy.

### **Early signs of cerebral palsy**

#### **At birth**

- At birth a baby with cerebral palsy may seem flaccid and floppy.
- Child may not cry immediately after birth and his skin may turn pale and blue.

#### **During the first year**

- The child may develop difficulties in feeding, sucking and swallowing. Child may choke or gag often. These difficulties may persist for months.
- The child may cry excessively and may seem very irritable or not cry at all and seem abnormally quiet.
- The child may show slower or delayed development compared to other children. The normal development of the children is as shown in Table 1.
- Child's body may stiffen when carried, dressed, washed, or during play.
- It may be difficult to carry the child as the body is too flail or stiff.
- When picked up after 3 months of age, the child may not be able to hold the head properly and it may fall behind or on the sides.
- The arm and leg movements of the child are diminished and the child may find it difficult to grip the toes or his hands.
- Arms and legs may twitch uncontrollably.
- The child may show some signs of impaired communication. The child may not smile upon looking at the mother. The child may not respond when his name is called.

- The child may not be able to use both his hands together in a coordinated manner e.g use both the hands to grip toys etc.
- There may be excess floppiness or stiffness, or lack of arm gestures, or control of face muscles. The child may not be able to point at things that he needs due to these impairments.

Table 1: Normal development of children  
 (\* REF: <http://www.cdc.gov/ncbddd/actearly/milestones/index.html>)

Age of the child	Developmental milestones to be achieved	
	Social and Emotional	Movement & Physical development
2 Months	<ul style="list-style-type: none"> <li>• Smiling at people</li> <li>• Bringing hands to mouth and sucking on thumbs</li> <li>• Makes an attempt to looking at people</li> </ul>	<ul style="list-style-type: none"> <li>• Can hold head up and begins to push up when lying on tummy</li> <li>• Makes smoother movements with arms and legs</li> </ul>
4 Months	<ul style="list-style-type: none"> <li>• Smiles spontaneously, especially at people</li> <li>• Likes to play with people and might cry when playing stops</li> <li>• Copies some movements and facial expressions, like smiling or frowning</li> </ul>	<ul style="list-style-type: none"> <li>• Holds head steady, unsupported</li> <li>• Pushes down on legs when feet are on a hard surface</li> <li>• May be able to roll over from tummy to back</li> <li>• Can hold a toy and shake it and swing at dangling toys</li> <li>• Brings hands to mouth</li> <li>• When lying on stomach, pushes up to elbows</li> </ul>
6 Months	<ul style="list-style-type: none"> <li>• Knows familiar faces and begins to know if someone is a stranger</li> <li>• Likes to play with others, especially parents</li> <li>• Responds to other people's emotions and often seems happy</li> <li>• Likes to look at self in a mirror</li> </ul>	<ul style="list-style-type: none"> <li>• Rolls over in both directions (front to back, back to front)</li> <li>• Begins to sit without support</li> <li>• When standing, supports weight on legs and might bounce</li> <li>• Rocks back and forth, sometimes crawling backward before moving forward</li> </ul>
9 Months	<ul style="list-style-type: none"> <li>• May be afraid of strangers</li> <li>• May be clingy with familiar adults</li> <li>• Has favorite toys</li> </ul>	<ul style="list-style-type: none"> <li>• Stands, holding on</li> <li>• Can get into sitting position</li> <li>• Sits without support</li> <li>• Pulls to stand</li> <li>• Crawls</li> </ul>

Age of the child	Developmental milestones to be achieved	
	Social and Emotional	Movement & Physical development
1 Year	<ul style="list-style-type: none"> <li>• Is shy or nervous with strangers</li> <li>• Cries when mom or dad leaves</li> <li>• Has favorite things and people</li> <li>• Shows fear in some situations</li> <li>• Hands you a book when he wants to hear a story</li> <li>• Repeats sounds or actions to get attention</li> <li>• Puts out arm or leg to help with dressing</li> <li>• Plays games such as "peek-a-boo" and "pat-a-cake"</li> </ul>	<ul style="list-style-type: none"> <li>• Gets to a sitting position without help</li> <li>• Pulls up to stand, walks holding on to furniture ("cruising")</li> <li>• May take a few steps without holding on</li> <li>• May stand alone</li> </ul>
1.5 Years	<ul style="list-style-type: none"> <li>• Likes to hand things to others as play</li> <li>• May have temper tantrums</li> <li>• May be afraid of strangers</li> <li>• Shows affection to familiar people</li> <li>• Plays simple pretend, such as feeding a doll</li> <li>• May cling to caregivers in new situations</li> <li>• Points to show others something interesting</li> <li>• Explores alone but with parent close by</li> </ul>	<ul style="list-style-type: none"> <li>• Walks alone</li> <li>• May walk up steps and run</li> <li>• Pulls toys while walking</li> <li>• Can help undress herself</li> <li>• Drinks from a cup</li> <li>• Eats with a spoon</li> </ul>
2 Years	<ul style="list-style-type: none"> <li>• Copies others, especially adults and older children</li> <li>• Gets excited when with other children</li> <li>• Shows more and more independence</li> <li>• Shows defiant behavior (doing what he has been told not to)</li> <li>• Plays mainly beside other children, but is beginning to include other children, such as in chase games</li> </ul>	<ul style="list-style-type: none"> <li>• Stands on tiptoe</li> <li>• Kicks a ball</li> <li>• Begins to run</li> <li>• Climbs onto and down from furniture without help</li> <li>• Walks up and down stairs holding on</li> <li>• Throws ball overhand</li> <li>• Makes or copies straight lines and circles</li> </ul>

## Motor symptoms

These are the symptoms associated with body movements and postures. Although caused due to impairment of the brain the signs are most often related to muscles causing abnormalities in muscle tone, strength, and coordination. As a child grows, skeletal and joint development is also impaired leading to deformities (curved spine, stunted growth, fixed joints etc). The commonest of the motor symptoms is delayed milestones i.e delay in achieving voluntary control of activities like head movements, rolling, turning, sitting upright, standing up, walking and speech.

## Signs associated with variation in the tone of the muscles

The most common and easily noticeable sign of cerebral palsy is abnormal muscle tone. As explained earlier the tone of the muscles is the tension in the muscles required to bring about movement. To bring about a movement in the joints the muscles work in pairs; there are muscles that initiate and carry out the movement, called agonists and there are muscles that need to relax to facilitate this movement, called antagonists. Antagonists also control the movement by resisting the excessive action of the agonists. Even something as simple as lifting the finger up requires a coordinated muscle action. Proper muscle tone allows limbs to bend and contract without difficulty, enabling an individual to perform movements smoothly.

Abnormalities of the tone are demonstrated as following signs:

**Hypotonia** – Characterized by reduced tension in the muscles, exhibited as flaccid, relaxed and floppy babies. Children may not be able to sit or stand for a long time and carry out arm movements in sitting and standing.

**Hypertonia** – Characterized by increased muscle tension. The movements are slow and laborious and sometime not possible as the antagonist muscles fail to relax. Children frequently exhibit common postures or patterns of movements and hypertonia is also associated with deformities of various joints, if not treated earlier in the childhood.

## Common postures and patterns of muscle stiffness observed in spastic cerebral palsy

1. Head twists on one side, the arm on that side stiffens and straightens out; whereas the arm on the other side bends in the elbow. Both the legs stiffen from the knees and straighten up, pressing the knees onto each other (Figure 1).
2. Shoulder and head presses back, both the legs straighten up with heels digging in. The arms are bent in the elbow and both the shoulder blades are pulled in.
3. The whole body arches backward like a bow with both the arms and legs stiffened and straight; head digging in the bed and spine curved backwards. (Figure 2)



*Figure 1. Common postures and patterns of muscle stiffness observed in spastic cerebral palsy*



*Figure 2. Common postures and patterns of muscle stiffness observed in spastic cerebral palsy*



*Figure 3. Scissoring of the legs*



4. When the child is lifted up the tension in the inner thigh muscles increases and both the legs cross giving the body a scissor like appearance. This position is frequently known as scissoring of the legs (Figure 3).
5. While walking the child may walk in an awkward posture of knees pulled together squeezing on to each other, foot pointing down and turned inside making the walk on his toes.
6. One of the rarely seen postures is that the head and stiffens and is pushed back while the hands curl, elbows bend forward on the chest.

**Dystonia** – Dystonia is characterized by fluctuating muscle tone. At rest the tone may seem normal but initiation of voluntary activity may lead to sudden stiffness. Sometimes the child may also appear floppy and weak unable to carry out the movements.

**Mixed tone**– In some children arms and legs may show increased tone on voluntary movement whereas the trunk may be hypotonic.

**Muscle spasms** – Muscle spasms are muscle contractions that are uncontrollable, sustained and painful.

**Clonus** – clonus is uncontrolled jerky muscle contractions that cause rapid tapping movement of the feet or flapping movement at the wrist.

## Signs associated with abnormal reflexes

A reflex is an involuntary response of nervous system without active cognition. They are meant mainly to be protective facilitating survival. There are various reflexes present in the infants that help them feed, protect from falling and help bring about coordinated movements in different body parts. Most of the movements in early childhood begin as reflexes which are later on learnt by the muscles and parts of the brain. As we learn to perform these movements voluntarily the reflexes become diminished. In cerebral palsy however these reflexes may not be integrated and may not diminish till later in childhood and may hinder voluntary movement. While some reflexes may be exaggerated some reflexes may fail to develop at all.

Some of the common reflexes that may persist till later in the childhood are as follows,

- **Palmer grasp reflex** – This reflex should disappear between 4 to 6 months. It is characterized by closing of the fist as the palm of the infant is touched.
- **Placing reflex** – This reflex should disappear by 5 months. As the infant is held upright and the heels touch the surface of the ground the legs curl up. Inability to integrate this reflex may result in difficulty standing and walking.
- **Moro (startle) reflex** – Moro's reflex usually integrates in 6 months. When the head of infant suddenly falls back the arms extended.
- **Spinal gallant reflexes** – It should disappear by 3 to 9 months. When an infant lies on his stomach the body curls to the side that is touched down.

- ***Asymmetrical tonic reflex*** – Usually this reflex should disappear at the age of 6 months. This reflex characterized by straightening of the arm and legs on the side where the neck turns and bending of elbow and knee on the opposite side.
- ***Symmetrical tonic neck reflex*** – This reflex integrates by 8<sup>th</sup> or 12<sup>th</sup> month. It is characterized by the infant assuming a crawling position when neck is extended.
- ***Tonic labyrinthine reflex*** – This reflex should disappear by three and half years of age. When the head of the infant is tilted behind, the back and body of the infant arches backwards.

## **Signs associated with Movement coordination and control**

Impairment of the tone, impairment of the balancing of the tone in various muscles and body parts causes abnormal and awkward movements. If the primitive reflexes persist the child is unable to perform various sophisticated voluntary movements as the limbs behave in a reflex pattern without his control. These signs may become more evident when the child is under stress or pain. Some movement anomalies may be caused due to voluntary activity but are absent at rest.

As explained earlier in the various types of cerebral palsy lack of coordination of movements mainly results in the difficulty of performing movements of extremity joints like wrist, hand and fingers and ankle, foot and toes. While performing these movements a child's brain needs to co-ordinate multiple joints and muscles and therefore they are very difficult. The incoordination in upper limb results in difficulty performing fine movements with fingers (buttoning, tying shoe laces etc.), overhead movements, crossing over to the other side and incoordination in lower extremities leads to disturbances in balance and gait. Children have clumsy movements. They cannot walk straight and follow a zig-zag pattern; they fall often while walking on an uneven surface. Children may also not be able to perceive the depth and find it difficult to climb up and down the stairs.

Gait disturbances include, inward or outward rotation of the toes, limping, walking on toes, legs scissoring in while walking leading to squeezing or brushing of knees onto each other. Children may lift there leg higher or drag it and shift the weight from one leg to the other, waddling to compensate for muscle weakness.

## **Signs associated with poor balance**

- Child may need to use support with both hands to maintain sitting position.
- Inability to maintain sitting position if there is even a slight perturbation or change in the position
- Continuous swaying when he stands and need to hold onto something
- Frequent falls
- Inability to perform quick movements.

- Gait deviations
- Inability to perform hand activities while standing or walking
- Fear of sitting or standing without support

### **Signs associated with abnormal oromotor function (movements of mouth, lips and tongue)**

Although caused mainly due to impaired tone and co-ordination of muscle movements. It is important to learn about oromotor signs as these are evident from early childhood. Oromotor difficulties are difficulties experienced by the children in performing lip, tongue, and jaw movements. Early oromotor difficulties are exhibited as inability or difficulty in sucking and swallowing, excessive drooling of saliva. Later the child may find it difficult to chew and impaired or absent speech.

Impaired speech could be because of impaired breathing articulating and voicing.

- ***Breathing*** – Breathing is controlled by muscles and inability to use these muscles in coordination results in breathing difficulty coughing and huffing difficulty frequent aspirations and respiratory infections.
- ***Articulating*** – Articulation is the process of coordinated use of jaw, tongue and lip muscles. Children may not be able to perform these.
- ***Voicing*** – vocal cords are also controlled by muscles and therefore children with cerebral palsy find it difficult to voice their speech effectively.

Another form of speech difficulty in cerebral palsy is Apraxia. This means poor transmission of the signals from brain to the muscles that are required for speech. Dysarthria is another one of the speech impairments common to cerebral palsy. Dysarthria occurs mainly because of the involuntary muscle contractions where the speech is slurred.

Although mainly a movement disorder various other systems may also be affected in cerebral palsy. There is a concomitant presence of visual and hearing deficits in majority of the children with cerebral palsy. The children may also have impaired cognition and intellect. Section B, associated problems will explain in detail about these symptoms.

## 5. Diagnosis

The diagnosis of cerebral palsy is confirmed based on the signs and symptoms exhibited by the child and results of various diagnostic imaging techniques like Magnetic Resonance Imaging (MRI), Computed Tomography (CT) and Electroencephalography (EEG). Various other tests are performed to diagnose associated impairments. This chapter will give you what signs and symptoms to look out for in a young child and seek immediate medical attention and how the diagnosis will be confirmed.

The most common basis of diagnosing cerebral palsy is delayed development of normal physical and cognitive function. The diagnosis of cerebral palsy involves the following steps.

**Observations by parents:** It is important for the parents to be vigilant for the presence of any of the early signs and symptoms of cerebral palsy as mentioned in the earlier chapter. If the child presents with any of those immediate medical attention needs to be sought.

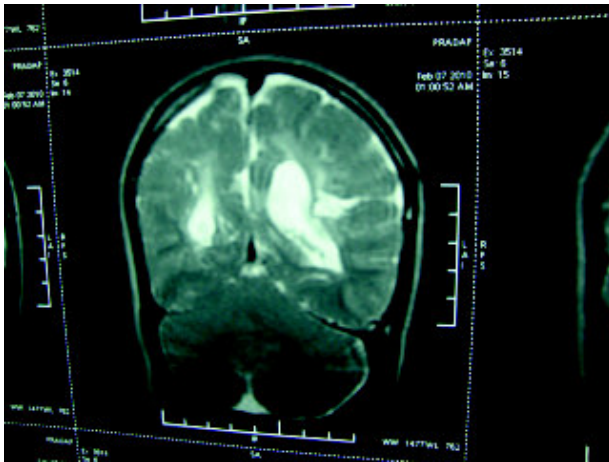
**Birth history:** Upon visit to the physician or pediatrician a detailed birth history will be taken in which a series of questions regarding the risk factors for cerebral palsy are asked to identify probable risk factors.

**Developmental history:** The doctor will then ask you about the developmental history of the child, to find out about any delay in performing motor tasks and displaying social behavior in comparison with normal standards.

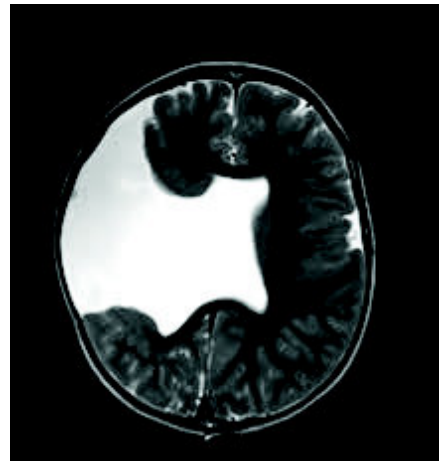
**Motor examination:** A detailed physical examination is carried out to evaluate the ability to perform various motor tasks, variations in the tone of muscles, impaired coordination and presence of abnormal involuntary movements.

**Reflex testing:** The clinician will then check for the presence of any abnormal reflexes or persistence of primitive reflexes later than the normal age.

**Administering special tests:** If there are any abnormalities identified in the above, the clinician will then ask for special investigations to identify the cause and the area of brain damage. These investigations include MRI and CT scan. These scans help to look at the brain to identify or rule out any injury to the brain (Figure 1) or structural anomalies (Figure 2) of the brain. This is important for diagnosis as well as to decide the further course of action, if the child needs any surgical intervention to correct the structural anomalies.



*Figure 1. MRI scans showing Periventricular Leukomalacia*



*Figure 2. MRI scan showing abnormal development of brain – schizencephaly*

**Identifying progression of symptoms:** Through repeat examination and detailed history the clinician will identify whether the symptoms are progressive or non-progressive. If the symptoms are progressive further investigations will be carried out to identify the cause.

**Obtaining second opinion:** After these steps usually a clinician will confirm the diagnosis of cerebral palsy. However it may be warranted to seek confirmation of diagnosis from a different clinician to avoid misdiagnosis.

**Identifying associated problems:** Cerebral palsy is known to lead to various associated impairments that are best managed if identified early. Therefore it is important that the examination and investigations are carried out even after diagnosing cerebral palsy to ascertain associated problems. Special investigations may be carried out for this purpose. A detailed clinical examination will be carried out for testing auditory, visual, cognitive, sensory, respiratory and gastrointestinal systems. Special investigations carried out for these are explained in detail in section B.

## **SECTION B:**

# **Associated Problems**



## 6. Epilepsy

Epilepsy occurs in nearly 50-80% of children with cerebral palsy depending upon the type of cerebral palsy. A seizure is defined as abnormal electrical discharge in the brain that stops the normal functioning of the brain. Even normal children have a risk for seizures, however this risk is significantly multiplied in the context of brain injury. Children who have recurrent seizures are said to be suffering from epilepsy. A convulsion is a common term in epilepsy and this denotes the motor component of the seizure.

Broad classification of seizures is in two main categories:

1. Generalised seizure
2. Focal seizure

The term generalised seizure indicates that the abnormal electrical signal affects both the hemispheres at the same time and leads to immediate unresponsiveness; whereas the focal convulsion denotes the limited localization of the electrical discharge with or without secondary spread. In a focal convulsion, it may appear that the child is responsive to begin with and towards the end of the event may turn unresponsive if there is a spread of the electrical discharge to the entire brain signifying a secondary generalisation of a focal seizure.

### **Generalized seizures:**

#### ***Tonic-Clonic Seizures or Grand Mal Seizures:***

Tonic-clonic are the most common type of generalized seizures and the most severe of all seizures. Symptoms include unconsciousness, convulsions and body rigidity. Violent shaking and loud noises are common.

During the tonic seizure phase, a person will appear to be stiff. The eyes roll, arms will extend, chest/arm/leg muscles will contract, the back will arch, and breathing may decrease or cease. He or she will have loss of consciousness with lips and face appearing blue.

The clonic seizure phase includes convulsions, muscle spasms and jerks. Limbs may shake or flex rapidly. Other symptoms include incontinence, and biting of the cheek or tongue. As the spasms gradually subside, the individual may sigh before breathing



resumes. It may take a few minutes for the brain to bring the seizure under control. As the person resumes consciousness, he or she may have a headache and body weakness and feel tired, drowsy, confused and lethargic. Regurgitation is likely. Full recovery can take few minutes or an hour.

### ***Myoclonic Seizures***

Myoclonic seizures include brief, involuntary, shock-like jerks to the arms, face, legs or torso muscles. It usually occurs without warning and resembles the reaction to an electrical shock. The episode lasts a second or two and causes an abnormal startle movement that often occurs on both sides of the body at the same time. Occasionally, only one side of the body, or one arm or foot is involved.

Consciousness is not lost when the rhythmic or random jerk pattern occurs. Jerks can occur as a singular event, in a sequence, in a pattern, or without a pattern. The jolt can be powerful enough to cause a child to fall to the ground. Myoclonic seizures can occur as a single seizure, or as a cluster of seizures.

### ***Atonic Seizures or Drop Attacks***

Atonic seizures are indicated by limp muscles and temporary loss of muscle tone that lasts less than one minute. The head will drop, posture will be lost, and the bodies will suddenly and forcefully collapse. A child's level of awareness may be altered. These seizures can occur several times a day. Children who experience atonic seizures may opt to wear protective headgear to guard against head and face injuries caused by the abrupt seizure that has little to no advance warning.

### ***Infantile Spasms***

Infantile spasms cause babies to experience a cluster of quick and sudden movements. The head falls forward and the arms flex when sitting, or when a baby positioned in a lying position appears to double up and jerk forward as if reaching for support. Infantile spasms occur when a child is between three months to two-years-old. This type of seizure in general leads to a bad outcome with developmental regression and increased long term risk of epilepsy. Early recognition of this type of seizure is very important as the long term outcome is extremely guarded in children who have infantile spasms. The spasms in themselves are very difficult to treat with 60-65% achieving freedom from spasms.

### **Focal Seizures:**

These are of two types, simple partial and complex partial events. In the simple partial events, there may a sensory (tingling, numbness etc) phenomenon or a motor (jerks, abnormal movements etc) phenomenon affecting one limb or a body part or the hemibody. The consciousness is preserved and continues to remain so till the end of the seizure. In the complex partial seizure the consciousness is impaired during the event.

## 7. Contractures and Deformities

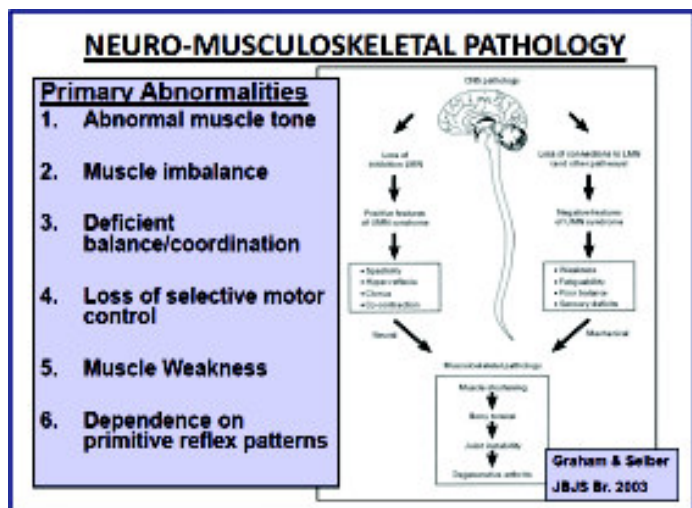
**Why Contractures and Deformities are common in Cerebral palsy which is a brain disorder?**

Cerebral Palsy is a neurological disorder affecting balance, muscle power, co-ordination and depending on severity causes mild to severe disability in daily living functions.

It is not an orthopedic condition, but the spasticity or tightness of muscles causes the bone to deform and twist leading to abnormal walking patterns.

The muscle tightness can also cause abnormal positioning of joints and this can lead to joint dislocation and instability of various joints around foot and ankle.

This involvement of muscle, bone and joint leads to characteristic deformities seen in children with cerebral palsy.



**What is spasticity and what are the signs and symptoms? Which contracture is typically seen in child with CP?**

The spasticity or tightness is seen more in muscles which cross two joints, hence gastrocnemius (calf), Hamstring (muscle that flex or bend the knee), hip flexors, biceps and long finger muscles which are primary offenders. Thus, the **equinus** (toe walking) position of the foot where the heel is always off the ground occurs because of calf muscle tightness. The toe walking causes the child to fall and lose balance. The hamstring and hip flexor tightness causes the knee to bend (**fixed flexion deformity**) and prevent upright stance posture. As the child grows, the muscle tissue gets stiffer leading to contracture of joints. Depending on muscle forces and the

weight bearing pattern, the foot can either deform outwards (Planavalgoid feet) or inwards (forefoot adduction and hindfoot varus).

The lower limb involvement can be bilateral (diplegia) or unilateral (hemiplegia) based on extent and site of brain damage. The overall limb pattern can vary from child to child and is mainly dictated by the stiffness (tone) of the mu



*Figure 2: Hip deformity: difficulty in performing sideways movement of hip*



*Figure 3: Hip deformity: difficulty in performing sideways movement of hip*



*Fig 4: Knee flexion deformity*



*Fig 5: Foot deformities*

## **Are there different types of muscle stiffness in a child?**

Intermittent stiffness (spasticity) and continuous stiffness (dystonia), and involuntary movement (athetosis) are different types of muscle tone disorder seen in children with CP. The severity of tone abnormality may change with age but diurnal variation may also occur depending on stimulation of child. A single assessment may not reveal the true extent of deformity and hence various scores have been described to evaluate the muscle stiffness (Ashworth Scale), walking potential (Gross Motor Function Scale) and overall functional disability (Pediatric evaluation of Disability Inventory - PEDI).

## **What Preventive strategies can be adopted for children with Cerebral Palsy?**

Precautionary measures for preventing worsening of stiffness should be started immediately after birth. The high-risk neonate must be evaluated and referred for Neurodevelopment therapy (NDT) as early as possible. Appropriate physical therapy methods help to stimulate the non-damaged areas of the brain to form new connections (brain plasticity) and reduce the abnormal tone. In infants and toddlers combination of PT and SI (sensory integration) helps the child to adapt to his level of function and coupled with orthotics preserves muscle length. Judicious use of orthotics like AFO for ankle equinus (toe walking), feet malalignment and knee deformity helps to maintain limb alignment. Orthopedic intervention in CP should not be carried out in isolation.

## **Is there any medical treatment for spasticity? Is botulinum injection safe?**

There are several medicines available for spasticity. These work on different parts of the nervous system. Drugs like Liofen, Pacitane, Tizanidine and Rivotril are commonly used but they also have side effects.

If the tone abnormality is significant and not controlled with medication or therapy, then local control of stiffness by Botulinum Toxin injection is preferred. This powerful neurotoxin is used as an intramuscular injection at various sites to reduce the stiffness. The dosage and sites of injection is individualized for each child based on thorough assessment using special scales. The target muscles are then localized by physical examination, ultrasound or Electromyography to achieve optimum benefit. Botulinum is used locally and has minimal side-effects, if used by experienced doctor and in the correct dosage. The limitation of botox use in spasticity is due to its temporary short term effect (around 6 months).

## 8. Communication Disorders

*Contributed By: Mrs. Gayatri Hattiangadi, Mrs. Vinaya Keer*

A child with CP may have delayed onset of language. There could be a considerable lag between his receptive language and expressive language. The child may have verbal language but it may be underdeveloped and comparable to age levels far lower than his chronological age and is thus deficient. There could be many reasons for this. A common reason may be that the child with CP may have co morbidities or associated problems such as hearing loss or cognitive impairments of moderate to severe degree due to the neurological impairment suffered in the early developmental period and this may prove a deterrent in acquisition of language. So, unless the multiple impairments are tackled, the child may never learn to speak or communicate effectively.

Motor deficits limit the child's ability to move around and experience the world around him leading to deficits in perceptual maturation which in turn affects their prerequisites for language development.

A common but perhaps, undetected factor for delayed onset of language may be poor speech and language stimulation. The parents and caregivers may be so harried and preoccupied by the child's health related problems that the time spent in normal bonding during caregiving may be otherwise spent in seeking right postures, feeding, changing, all of which are deviant and require especial care in these children. Thus, they may not be talking as much to these children who are already at a disadvantage for speech /language development. Thus children with CP may further show a delay due to poor or inadequate language stimulation. It is also seen that due to the law of reciprocity in communication, there needs to be turn taking and listeners and speakers need to regularly change roles. When the child does not respond to caregiver's attempts at speaking, over a period of time, the caregiver's attempts reduce and in many cases, may altogether fade away. So the child may be just held, moved, placed, fed, bathed, dressed, placed in the crib without accompanying all these activities with effective speech and language.

### **Speech Disorders in Children with CP**

Due to the severe motor deficits the child has, he may have severe anarthria wherein the child may have severe weakness and incoordination of the speech musculature

and find it difficult to speak. Vocalisations may be used for communication but the child does not have the articulatory agility to develop speech sounds.

## Difficulties in Breathing for Speech Faced in Children with CP

### *Breathing for speech*

The patterns for breathing for life (vegetative breathing) is different from breathing for speech, in that, the former has almost a proportional duration, that is almost 1:1 in terms of time taken for breathing in and breathing out. However, for speech breathing the ratio of time for breathing out is 1:3 or 1:5 which means that the exhalation phase is much more prolonged and voicing occurs which is further modified into speech sounds on this outgoing airstream.

### Difficulties in breathing for speech

In children with CP, deficits in speech breathing are commonly seen. The rapid and shallow breathing patterns when utilized for speech may result in

- Short and abrupt vocalizations
- Reduced phrase length
- Short rushes of speech
- Unintelligible speech due to reduced audibility when the breath supply runs out towards end of utterances
- Sudden involuntary movements lead to abnormal increase or decrease in volume of speech and pitch fluctuations.

**Speech disorders** may be varied and typical to the pattern of motor deficits that each child manifests.

- A child with **spastic** type of CP would have severe respiratory weakness, short breath groups used which may not last the child's utterance, strained strangled voice quality and weakness, hypertonicity and hypernasality and slow rate of speech with distortions of speech sounds. Sometimes, persistence, exaggeration and irregular appearance of feeding reflexes may interfere with articulatory movements causing articulatory deficits.
- A child with **flaccid** type of CP, may have the overriding pattern of weakness and hypotonicity with all aspects of speech being affected.
- A child with **athetoid** type of CP may have severe distortions in articulation, abrupt changes in loudness and pitch and repetitions in articulatory movements.

The management for the above primary order and secondary order problems will be presented in the chapter on management.

## 9. Feeding and Swallowing Disorders

*Contributed by: Mrs. Gayatri Hattiangadi, Mrs. Vinaya Keer*

**Feeding** pertains to the process of eating until the triggering of the swallow reflex. Thus it deals with the placement and positioning of bolus in the mouth and keeping it in place by the lip closure (labial seal) and the grooving of the tongue, mastication of food in the mouth mixing it with saliva, gathering it after mastication until the food is transformed into a cohesive bolus and propelled towards the back of the mouth in readiness for the swallow to occur.

### Feeding Disorders

- An infant with CP may have a weak suck and may tire soon while breastfeeding. The mother may perceive it as though child has had his fill whereas the child is still hungry and will hence, not sleep well, be irritable and will not thrive well, in the long run.
- Children with spastic type of CP may present with spastic bite (strong involuntary bite which is difficult to release), increased sensitivity to taste, temperature and pressure which affect swallowing and feeding patterns.
- Children with flaccid type of CP may have excessive drooling and dribbling of food and liquid due to poor lip closure, poor mastication and poor bolus control leading to pocketing of food in the mouth, as also prolonged mealtimes. This may be seen due to lack of coordination while chewing, poor tongue mobility and poor lateral movements of the jaw.
- Children with athetoid type of CP may have problems in positioning food in mouth, discoordinated swallow, owing to sudden involuntary movements
- In all these children, aspiration may occur especially for thin liquids which may trickle downwards before the child's readiness to swallow and cause some drops to enter into the airway rather than into the esophagus leading to violent coughing.

- These children, thus may develop strong preferences for certain foods and strong avoidance towards others, based on their previous experiences with textures and taste.
- They may limit to a small variety of foodstuffs and hence not get adequate nutritional requirements and are at a risk for malnutrition and dehydration
- Some of the children could also be having sensory issues wherein they may not be able to tolerate some textures and vomit frequently. This further adds to the problem of feeding and needs the intervention by the Occupational Therapist as well.
- As the child grows older, there are behavioral issues too and the child may throw temper tantrums if forced to have food other than his preferred ones. The child may refuse food vehemently and if forced may hold it in mouth for a long time and spit it out eventually.

Owing to these difficulties, caregivers of these children find feeding them a difficult cross to bear. Feeding time, in typical growing children is characterized by communication and bonding and is often a fun time, enjoyed both by the child and his caregiver, marked by singing of rhymes and children songs, caregiver child interaction, and storytelling. However, this is often a frustrating experience for both, the child with CP as well as his caregiver. Thus there is an uneasy compromise where some types of foods are apparently agreed upon. The caregiver feels that something which the child easily accepts at least can be given in a greater volume and with greater ease, ensuring nutritional intake. Thus, it is not uncommon to see the child with CP even at 4 years and beyond to be on a milk diet or only milk, bread and biscuits. Thus, these children need to be taken up for intervention at the earliest. The management of feeding disorders is mentioned in the section on management.

**Swallowing** pertains to the oral preparatory, oral, pharyngeal and esophageal stages of swallowing. The first two stages have been discussed earlier. Once the bolus is propelled to the back of the mouth, the swallow reflex is triggered and then onwards it becomes a reflexive process and the bolus is propelled towards the back of the oral cavity which is the pharynx. Once the pharyngeal stage begins, the entry to the nasal passage and laryngeal passage (airway) is closed off, vocal cords adduct and the bolus is propelled to the level of the upper esophageal sphincter (UES) which is the upper valve of the esophagus. It relaxes and food enters the esophagus and the UES contracts again. Due to the peristaltic movements of the esophagus, the food is successively propelled downwards, until it reaches the lower esophageal sphincter (LES) which is the lower valve of the esophagus. When the LES relaxes, the bolus enters into the stomach and the LES contracts again thus preventing the reflux of food back into the esophagus. This completes the process of swallowing. The same process repeats itself through the entire meal and also occurs when we swallow saliva many times through the day and lesser number of times at night.



## **Swallowing Disorders**

Children with CP could have moderate to severe dysphagia due to various reasons. Problems related to oral preparatory and oral phases have been earlier presented. Some of the commonly seen signs and symptoms of pharyngeal and esophageal dysphagia (swallowing disorders) are presented below:

- Swallow reflex is sluggish or severely delayed.
- Gag reflex is hypo or hypersensitive. If the latter, they may gag and bring out food frequently. Some change in texture especially if it is a bit grainy, may trigger the gag reflex.
- Another common feature in children with athetoid and spastic types of CP is discoordinated swallow which may precipitate aspiration causing severe coughing. This happens more in case of thin liquids such as water and milk.
- When this happens frequently, the child may have aspiration pneumonia. Some of the signs of it may be reddening of eyes, spiked fever, chills, failure to thrive or weight loss and the child may require hospitalization.
- Esophagaeal motility too could be affected as is seen in many GI disorders faced by these children.
- Due to gastrointestinal problems, these children may often be prone to have gastroesophageal reflux (GERD). The management of this type of dysphagia falls in the domain of the gastroenterologist.

## 10. Visual Impairments

*Contributed by: Dr. Sharad Partani*

Eyes are the most wonderful creation of the nature. We all experience this beautiful world through our eyes.

A good quality vision is very important for overall development of the child. It helps in normal development of brain & hence leads to normal psychological, social & physical development of the child.

### **Functioning of visual system:**

Visual system functions in a very interesting way. The working of an eye can be compared to an advanced camera & that of visual system can be compared to an electric circuit.

To visualize any object, the complex lens system of our eyes focuses that object on a single sharp point on the most sensitive part i.e. macula on the back of our eyes i.e. retina. This creates an electric impulse that is carried to the visual cortex (area of brain related with vision) through nerves (wires) where the image is perceived. Hence, to see the object clearly, eyes & brain with the in between wiring should function normally.

Any problem that affects any of these components can lead to visual impairment.

Various studies have shown 45 to 70 % children with Cerebral Palsy (CP) suffer from one or more eye problems. So any child diagnosed with CP should undergo a complete eye examination as early as possible.

### **Eye Examination:**

This should ideally be carried out in the surroundings where the child is most comfortable (Familial Environment), usually at the rehabilitation centers. This gives an additional advantage – as teachers are immediately available to be educated about child's difficulties & for any interventional suggestions if required.

Child must be seated comfortably either on their parent's lap or in an adaptive wheel chair.

**Visual acuity (VA) :**

Presenting visual acuity recorded monocularly with various charts & techniques depending on child's cooperation & Age. In extremely uncooperative child, VEP (Visually Evoked Potential ) – a technique of objective recording of visual potential, is done.

**Refraction:**

To check for any requirement for glasses, every child must undergo refraction under cycloplegia.

**Ocular motility:**

Eye movements are evaluated by moving highly interesting colorful bright object in all six gazes.

In uncooperative patients, The Doll's Head Tilt Test is used to asses' ocular motility.

Cover Test, Alternate Cover Test, Prism bar Test, Hirshberg Test, Krimsky's Test are carried out to detect strabismus (squint).

Presence of Nystagmus is noted.

**Anterior Segment Examination:**

Detailed examination of front part of the eye is carried out with hand held slit lamp or a standard slit lamp biomicroscope.

**Posterior Segment Examination:**

After pupillary dilatation, the back part –fundus of the eye is examined with direct or indirect ophthalmoscope.

This Record of all findings is maintained properly.

**Eye Problems in Children with CP:**

As already stated 40 to 70 % children suffer from eye problems. This can be because of problems in the brain or in the eye. Let's consider the eye problems.

**Impairment of Vision:**

If rays coming from any object falls either in front (myopia) or back (Hyperopia ) of retina, the image of that object appears burr.

*Myopia (near sightedness)* – they can see close objects clearly but distant objects are blurr.

*Hyperopia (far sightedness)* – they can see far objects clearly , but near objects are blurr.

Some children have Astigmatism or blurry vision caused by abnormal corneal curvature.

**Symptoms** are blurred vision, eye fatigue, headache, bumping into objects , holding objects close to face , squinting of eyes.

This can be **corrected** with appropriate glasses or contact lenses. Seeing clearly helps improving incidental learning or learning that takes place by observation.



Figure 1: Glasses



Figure 2: Contact Lenses

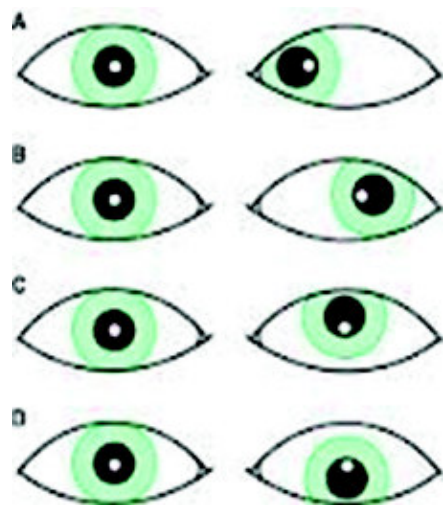
### Ocular Motility Problems:

Child with CP may experience in-coordinated eye movements due to problems with muscle tone, which in turn affects depth perception as well as hand eye coordination.

Sometimes crossed eyes occurring in early life can be a clue for a possibility of CP to the clinician

The types are:

- Eye turns in towards the nose (Esotropia or Esophoria **Fig. 3. A**)
- Eye turns out towards the ears (Exotropia or Exophoria **Fig. 3. B**)
- Eye turns up (Hypertropia Or Hyperphoria **Fig. 3. C**)
- Eye turns down (Hypotropia or Hypophoria **Fig. 3. D**)



The other motility problem is nystagmus or dancing eye – this is involuntary movement of eye. This is approximately present in about 15 % of child.

Figure 3

These eye problems are managed with appropriate glasses, Prisms or Corrective surgeries.

### **Amblyopia (Lazy Eye) :**

The brain suppresses the blurred images from the affected eye. This leads to “Lazy Eye”. If refractive errors or eye motility problems are not corrected before age of 8 years , the potential of vision is not developed in that eye & the eye becomes amblyopic - lazy eye.

To prevent this, early diagnosis & treatment of refractive errors & squint along with patching exercises to stimulate the lazy eye will help immensely.



*Figure 4*

### **Cortical Visual Impairment (CVI):**

If the child is found to have difficulty of sight despite normal eye , cortical visual impairment is suspected.

This is caused by damage within brain. This damage prevents the child from correctly receiving & interpreting the information from the eyes. This difficulty varies depending on the amount & location of damage within the brain.

A child with CVI may have difficulties:

- Knowing precisely where the things are in three dimensions. This can make it difficult for the child to move around safely e.g. using stairs.
- Seeing different things at the same time – e.g. finding a toy on a patterned carpet or seeing something that is pointed out in the distance amongst other things
- Recognizing familiar faces , objects & places

They may also have problems with:

- Focusing on looking at a close object
- Making fast eye movements

- Eyes getting tired more quickly than other children's. This means that their ability to see clearly vary from time to time
- Loss of Visual Field: The field of vision is everything you are able to see when you look straight ahead. Field loss means parts (s) of visual fields are missing or appears blurred.

These can be

- Peripheral loss of field
- Central loss of field- as like seeing after holding your fist in front of your eyes
- Scotomas- isolated spots are missing from your vision
- Islands of vision – you can see only scattered spots
- Hemianopia – right Or Left; Upper or Lower half of the field is missing.

CVI does not usually get worse & vision can sometimes improve over a period of time. However, even when there is improvement, a child's vision usually remains impaired to some extent.

### **Treatment of CVI:**

There are no medical treatments available at present. So efforts are made to manage the condition through the use of spectacles, contact lenses & low vision aids.

Stimulation of brain by using bright & colorful objects can be tried. We have to make sure; the rooms should always be brightly lit whenever the child is doing any activity.

### **Other Eye Problems:**

These are not that common

- Partial or Complete Optic Atrophy
- Ptosis ( droopy eyelid )
- Retinopathy Of Prematurity
- Peter's Anamoly

### **Summary**

Ocular abnormalities are very common in children with CP. Parents & health care workers should be aware of the eye problems & the activities that pose problems because the child doesn't seem to pay attention, best positions for visual activities & eye hand coordination.

Early intervention will help in child's visual, physical, psycho social & academic development. So a complete eye examination is sought as soon as a diagnosis of CP is made & yearly thereafter.

# 11. Auditory Impairments

*Contributed by: Mrs. Gayatri Hattiangadi, Mrs. Vinaya Keer*

In many children with CP, hearing impairment (HI) may be an associated problem. Difficulty in concentration and short attention span is commonly seen in children with CP and this difficulty is greatly increased when the child is also having a hearing loss. Hearing loss may be difficult to diagnose as the child with CP may not show a good response to sounds even when there is normal hearing sensitivity, as owing to motor deficits, he may not be able to localise in the direction of sounds.

- Some signs of HI are severe inattention, that is, no eye blink or changes in breathing pattern may be seen even when loud sounds are presented.
- Some children may show inattention to soft and moderately loud sounds and show a hypersensitivity to loud sounds by showing a severe startle response.
- The child with CP may have a conductive hearing loss (affecting the outer ear and middle ear) due to hard wax blocking the ear canal, fluid filled in middle ear, perforation of tympanic membrane, any middle ear infections, etc.
- Others may have mild or moderate degree of sensorineural hearing loss (SNHL) caused due to damage to the brainstem, auditory nerve or cochlea. According to Fisch (1969), total deafness is never present, unless caused by some other factor, and a very severe hearing loss is uncommon.
- Children with athetoid type of CP may also have a high frequency sloping SNHL which requires intervention but may often be missed as child responds well to even soft sounds of the low frequencies.
- Many children may be having both a sensorineural component as well as a conductive component which is termed as a mixed hearing loss which requires treatment planning for both types of hearing impairments.
- Hearing impairment creates a complication in the acquisition of language development and causes severe receptive language deficits and proves as a major deterrent to language development.

Hearing loss needs to be detected at the earliest to facilitate effective treatment planning.

## 12. Respiratory Complications

One of the major concerns for parents of children with cerebral palsy (CP) is regarding the respiratory problems. Breathing difficulties cause decreased oxygen supply to the whole body which eventually affects the growth of the child. So it is essential to prevent and treat promptly any breathing problems in children with cerebral palsy. It will hamper the growth of the brain and various organs of the body giving rise to many complications. Children with CP, especially those with cognitive impairment, have a significant risk of developing respiratory problems. Respiratory health is dependent on a variety of parameters, like the child's ability to breathe and cough effectively, along with his/her ability to cope with respiratory infections. One needs to prevent complications with respiratory problems as they may lead to life-threatening conditions. Therefore, caregivers must be aware and well versed with various ways to prevent and tackle the respiratory problems. Here we describe the common respiratory issues associated with CP along with ways to treat them.

The difficulties are manifested based on the pattern of neuromuscular difficulties in them.

- Children with **spastic** type of CP :- present with severe rigidity of musculature of thorax and abdomen, resulting in rapid and shallow breathing, reverse breathing patterns wherein the muscles of expiration are active during inspiration thus allowing very little air to be taken in and muscles of inspiration active during expiration leading to incoordination during breathing.
- Children with **flaccid** type of CP present with severe weakness of the respiratory muscles thus leading in shallow breathing and incomplete cycles of inspiration and expiration leading to insufficient air intake.
- Children with **athetoid** type of CP predominantly present with incoordination, sudden stoppages during breathing or prolonged phases of either expiration or inspiration based on when they have involuntary movements.

These aberrant breathing patterns lead to these children having oxygen deprivation to some extent and overall lead to the child having failure to thrive, poor immunity and vulnerability to contract infections. The difficulties in speech breathing would be discussed in the section on speech disorders.



## **Causes of respiratory problems:**

As compared to an unaffected child, a child with CP has a lower level of activity and is unable to exercise or take deep breaths. In CP, the damaged brain is unable to send appropriate signals to the muscles of the body, which causes the muscles to become weak and loss of control over the movements. The weak respiratory muscles and lack of coordination give rise to respiratory problems. There is weakness in the oromotor (mouth, tongue, face, jaw) muscles which gives rise to difficulty in swallowing the saliva leading to its accumulation in the mouth and throat. The weak chest muscles are unable to cause a forceful cough. So the airways are not cleared of the respiratory secretions completely. This can give rise to recurrent infections. Chest infections can also be attributed to spinal deformities like curvature of the spine (scoliosis, kyphosis), abnormal muscle tone (spasticity, dystonia) which lead to restrictive lung disease making lung expansion difficult. All these defects make the breathing laborious which can lead to respiratory dysfunction, and in extreme cases lung failure. Poor nutrition in CP children also contributes to their poor resistance to infection and lowered immunity. In some severe cases of CP, the child's airways may be underdeveloped which can also cause respiratory distress. Therefore, every child with CP should be thoroughly and regularly assessed to rule out respiratory problems.

## **Common respiratory problems associated with cerebral palsy are:**

- Drooling
- Aspiration
- Respiratory infections (upper and lower)
- Airway obstruction (stridor or wheezing)
- Snoring and sleep apnea
- Restrictive lung diseases
- Chronic lung diseases

### **1. Drooling**

Drooling is dribbling of saliva from the mouth and occurs in about one third of children with CP. The weakness and a lack of coordination of the muscles in the mouth, face, head and neck, make it difficult to swallow the saliva. Poor posture, jaw instability, nasal obstruction and speech disorders may also contribute to drooling. It may also be a side effect of some anti-epileptic medications.

#### ***Complications due to drooling:***

Children with excessive drooling may face many issues like choking spells, difficulty in eating, soreness of the neck and skin around the mouth. These children are also susceptible to chest infections and pose a higher risk of transmitting infections. This makes it essential to identify the underlying cause of the drooling.

***Treatment options:***

On the basis of the history and clinical examination of the child, your pediatrician can refer you to an ear, nose and throat (ENT) specialist and a speech therapist. Three primary modes of treatment have been tried for the reduction of drool. These are:

- Oromotor therapy involves exercises to strengthen the muscles of the mouth, tongue, cheeks, neck and face and improve their coordination. This improves mouth closure, tongue movements, swallowing and jaw position. It also improves sensory awareness. This is usually done by a speech therapist.
- Medications to reduce the production of saliva, for example glycopyrrolate.
- Surgery can be carried out to either reduce the amount of saliva or to divert the saliva to the back of the throat in order to facilitate swallowing.
- Recently, a fourth method involving the injection of the botulinum toxin (Botox) into the salivary glands has also proved to be effective in reducing salivary secretions.

**2. Aspiration**

Aspiration occurs when food, liquids, saliva, vomit or other secretions go into the lungs. Aspiration may occur due to lack of coordination of swallowing, abnormal protective gag reflex or gastroesophageal reflux (when food comes back up the esophagus after having gone down). Difficulty in swallowing and excessive salivation can also contribute to aspiration. It can cause chronic damage to the lungs.

***Signs and symptoms:***

- Choking or gagging while eating,
- Breathing difficulty while eating
- Coughing
- Recurrent infections

However, as mentioned earlier, some children may aspirate without producing any of these symptoms due to the absence of a gag reflex. In such cases, aspiration is suspected when the child gets repeated episodes of infection or pneumonia, called aspiration pneumonia.

***Diagnosis:***

- A routine chest x-ray may come up with “dirty lungs” which is a classic sign of chronic aspiration. However, a chest x-ray alone is not sufficient in revealing the cause.
- A test called the modified barium swallow provides information about the child’s swallow. It is carried out by a radiologist usually with the help of an occupational or speech therapist who feeds the child food of different

consistencies, usually liquids, to analyze how he/she swallows. A liquid metallic element called barium is mixed into the food and fed to the child in the x-ray department, the way he/she is usually fed at home or at school. When the child swallows, the barium in the food shows up on x-ray and reveals whether the food is going into the esophagus (where it should go) or into the lungs.

- Aspiration of the child's own saliva can be investigated with a nuclear medicine test called a salivagram. Like the modified barium swallow, a salivagram shows the flow of saliva through the esophagus and stomach.

*As parents what you can do:*

- Proper positioning of the child during the feed. The child should be held upright with neck in the flexed position. It is best to keep the child in a CP chair or any other chair with a head support.
- Small, frequent feeds.
- Appropriate consistency of food is preferred.

For example, in many instances, pureed foods are swallowed correctly, but liquids are aspirated.

In such cases, it is advised to avoid giving liquids on their own. It is better to thicken their consistency by using flour, cereal or thickening agents. The child has to simply avoid foods that give him/her trouble. The recommendation of a particular food type can be taken from the speech therapist and dietician. The modified barium swallow can help to identify the food type i.e. liquid, semi-solid or solid, that causes aspiration in a particular child.

- Oromotor exercises.

You can learn to do oromotor from a speech therapist than can be done regularly at home. This will help the child to swallow better.

- Feeding tube (Ryle's tube or PEG)

Ryle's tube is a feeding tube which is put from the nose into the stomach. This tube is a short term, temporary option for feeding. Your doctor may recommend this if your child is getting recurrent aspiration and is unable to maintain proper food intake.

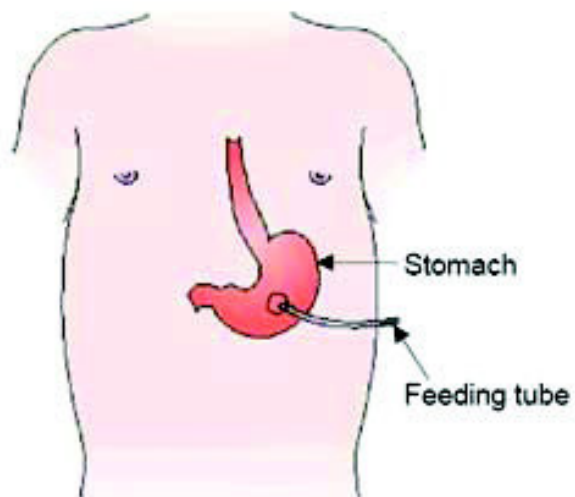


Figure 1: Feeding Tube

PEG (percutaneous endoscopic gastrostomy) is a long term and better option for feeding in children who have poor oromotor control and poor nutritional intake. A gastrostomy tube, also called a G-tube, is a tube inserted through the abdomen that delivers nutrition directly to the stomach, allowing the child to be fed without having to swallow. Once in the stomach, the food is digested normally through the intestinal system. Pureed foods or liquids, along with crushed pills or liquid medication can be put through the G-tube. A gastrostomy is a common procedure taking only about 30 to 45 minutes. Usually, the G-tube has to be changed every three months.

### *Side effects of the G-tube*

- Irritation and soreness of the skin around the tube.
- Skin infections can also develop at the site where the G-tube enters into the abdomen. However, this is usually a local infection and can be easily treated with antibiotic ointments.
- Other less common side effects may be; worsening of existing gastroesophageal reflux or onset of reflux.

### *Can my child still eat by mouth?*

Having the placement of a G-tube does not usually prevent the child from eating by mouth. If the tube is placed due to the child's inability to eat enough food, i.e. if it is being used as a supplement to feeding by mouth, then the child can certainly continue to eat by mouth as well. However, if the tube has been placed because the child has a history of aspirating everything he/she eats, then it will be recommended that the child avoid eating by mouth.

## **3. Respiratory infections**

Respiratory infections refer to any of the various infections involving the respiratory tract. These are usually further classified as Upper Respiratory Tract Infections (URI) and Lower Respiratory Tract Infections (LRI). Common respiratory infections are either viral or bacterial. Viral infections are usually self limiting and take about 7 to 10 days to resolve. Bacterial infections require antibiotics to be prescribed by a doctor.

### *Upper Respiratory Tract Infections (cough, cold, sinusitis, sore throat)*

These infections are caused by an acute infection which involves the structures of the upper respiratory tract like the nose, sinuses, throat, and larynx (voice box). These commonly include common cold, sinusitis and sore throat. URTI may happen as a result of nasal blockage, inability to maintain proper mouth hygiene or low immunity (poor nutrition).

### *Signs and symptoms:*

- Onset of symptoms usually begins 1–3 days after exposure. The illness usually lasts 7–10 days. Symptoms of URI's commonly include cough, sore throat, runny

nose, nasal congestion, headache, low grade fever, facial pressure and sneezing.

- Laryngitis will cause hoarseness of voice. Enlarged tonsils and pain in the throat while swallowing.
- Breathing difficulty.

### ***Lower Respiratory Tract Infections (pneumonia, bronchitis)***

Lower respiratory infections, such as pneumonia or bronchitis, tend to be far more serious conditions than upper respiratory infections.

Pneumonia is the infection of one or both of the lungs. This is caused due to chest infection which can be either bacterial or viral. The small airways in the lungs get swollen due to this infection and produce more sticky fluids which block the airways and reduce the amount of oxygen getting into the body. If your child has pneumonia then an x-ray will show fluid accumulation in the lungs. It is important to consult a pediatrician who decides the treatment to be administered based on various tests. Hospitalization may also be required in cases of severe infection.

### ***Signs and symptoms:***

- High fever
- Difficulty in breathing - you might notice that your child's breathing has become laborious and you may also notice ribs being sucked in when he/she is breathing.
- Cough and sputum
- Irritability
- Pain in chest especially during coughing
- Tummy aches
- Vomiting

### ***Treatment options:***

- Fluids – plenty of oral fluids to be given to prevent dehydration
- Antibiotics – To destroy the organisms causing infections.
- Medicines – Medicines for fever, e.g.- paracetamol and anti-inflammatory drugs, should be given to avoid very high fever. Other medicines like antacids and anti vomiting may also be required if the child has nausea or vomiting.
- Oxygen - in some severe cases where blood oxygen levels drop below normal range, oxygen supplementation is required. This can be given by nasal prong or mask. Usually after acute infection is resolved, oxygen levels may come back to normal. Thus, oxygen requirement in acute conditions is only temporary.
- Chest physiotherapy – Because the chest muscles are weak in CP, chest

physical therapy helps to clear the airway secretions and remove the blockage. This helps the child to cough up and breathe more comfortably.

***As parents what you can do:***

- It is important to give your child fluids to prevent dehydration as most of the children refuse to eat.
- Give them ample rest
- Keeping your child propped up on pillows rather than lying them flat may also be more comfortable
- Avoid smoking around your child
- If your child has chest pains, with guidance from your doctors, oral pain killers can be administered.
- Avoid cold food or drinks and preferably give the child warm water for drinking. warm water –avoid cold food /drinks
- Make sure to give medicines as prescribed and in a timely manner.

**Bronchitis**

It is an inflammation of the mucous membranes of the bronchi (the larger and medium-sized airways that carry airflow from the trachea into the more distant parts of the lung).

***Signs & symptoms:***

- Fever
- Cough

***Wheezing***

- Allergies
- Decreased oxygenation – SpO2 monitor is used to detect oxygen levels in the blood. Handy, portable, pocket-sized SpO2 monitors are available which can be used at home.



Figure 2

***Treatment options:***

- Nebulization – This is a technique where medicines are given in the form of gas through a face mask. A liquid medicine is poured in a container attached to the mask. The machine attached converts this liquid into steam which is inhaled by the child. This increases the amount of medicine reaching deep into the lungs



Figure 3

which opens up the airways and reduces wheezing. The swelling in the airways goes down and the secretions are thrown out. Commonly used medicines are beta agonists, steroids.

- Oxygen – This can also be given through the nebulizer mask to improve oxygenation and to make breathing comfortable.
- Antihistamines – If the child gets recurrent wheezing associated with a particular reason, e.g. dust, pollen, mold, seasonal variations, then antihistamines are helpful for the allergic symptoms.

#### **4. Airway obstruction (stridor or wheezing)**

An airway obstruction is a blockage in the airway. It may partially or totally prevent air from getting into the child's lungs. Some airway obstructions are life-threatening emergencies. They require immediate medical attention. It can be broadly classified into being either upper airway or lower airway obstruction. The most common complications caused by airway obstruction are stridor (upper airway) and wheezing (lower airway).

A high-pitched sound heard during breathing (inhalation) resulting from turbulent air flow in the larynx (where the vocal cords are located) is called stridor. There are many causes of stridor. The most common cause is the weakening of cartilage in the airway called laryngomalacia and results in partial airway obstruction. Low muscle tone in the throat and face may cause the tongue to fall to the back of the throat, which intermittently blocks the airway. This problem does not easily disappear, although positioning the child on his/her stomach may resolve the problem.

##### ***Signs:***

- Noisy inhalation
- Breathing through the mouth
- Labored breathing – Use of neck abdominal muscles and retraction of rib cage.
- Cyanosis – Bluish discoloration of the lips, fingertips, nails, skin. This happens because of low blood oxygen levels causing decreased supply to the body. This occurs in severe cases and has to be treated immediately as very low oxygen levels can be life-threatening.

##### ***Treatment options:***

- Seek immediate medical advice from your doctor.
- Oxygen – If blood oxygen levels are low, the child may require long term oxygenation at home.
- Nebulization – As described above (section on bronchitis)

- Ambu bag – If the stridor is causing respiratory distress and the airways are collapsing then ambu bag ventilation may be intermittently given to the child at home. Ambu bag is an equipment where a balloon like bag is attached to a breathing mask. One has to put the mask on the child's face and pump the balloon with the other hand. This has to be used only when prescribed by a doctor.



Figure 4

- Tracheostomy – In severe cases where oxygen levels remain to be low, surgical option of tracheostomy may become necessary. In this procedure, an opening is made in the airway in front of the neck and a tube is put through this opening. This bypasses the upper airway obstruction that is causing the stridor. Hence, the child can breathe more comfortably through the tube and oxygen levels are maintained.

#### *As parents what you can do:*

- Positioning - Most children with stridor seem to be less noisy and more comfortable lying on their stomachs.
- Post tracheostomy care – Frequent suctioning may be required through the tracheostomy tube. The tube has to be kept clean to avoid infections.
- Ambu bag – Doctor may advise the parents to use an ambu bag at home during episodes of severe stridor (as described above).
- Nebulizer at home – Portable, home nebulizer devices are readily available which are easy to use.
- Wheezing – This term generally refers to lower airway obstruction. As described in bronchitis section.

## **5. Snoring and obstructive sleep apnea**

Snoring is the sound which results from the vibration of structures in the respiratory tract due to obstructed air movement during sleep. Snoring can sometimes be an indication of a serious obstruction of the upper airways, especially when it is accompanied by bouts of apnea (cessation of breathing). Obstructive sleep apnea can lead to severe lung or heart disorders or even death if left unchecked and untreated.

Obstructive sleep apnea is a condition in which there are significant pauses in the child's breathing pattern during sleep. It is characterized by loud snoring with short periods of silence in which the snorer struggles unsuccessfully to breathe. Breathing resumes after several seconds of such laborious effort when a loud snort forces the airways to open. This is usually accompanied by the child awakening partially, at times failing the arms or kicking or experiencing a total body spasm. The child may then resume sleeping only to go through this painful sequence of events all over



again. These problems are considered to be pathologically significant when the child's apnea lasts longer than 20 seconds and occurs more than 7 to 10 times an hour or 30 times per night.

### ***Causes of sleep apnea:***

Possible cause of sleep apnea in children with cerebral palsy is abnormal muscle tone hypotonia, spasticity or dystonia, enlarged tonsils or adenoids due to infections, structural abnormalities of the head or neck. During the daytime, muscles in the head and neck keep the airway passages open. During sleep, muscle tone decreases, allowing tissue to come closer together and these large tonsils and adenoids tend to block the airway for long periods of time. Other tissues in the nose, neck and the tongue also contribute.

### ***What are the symptoms of obstructive sleep apnea?***

- Loud and laborious breathing
- Snoring
- Sweating heavily during sleep
- Irritability or other behavioral problems like hyperactivity or antisocial behavior
- Sleeping in odd positions
- Morning headaches

### ***Treatment options:***

- It is recommended to see a sleep specialist if the pediatrician suspects sleep apnea who may conduct various studies including upper airway evaluation, sleep study known as polysomnogram.
- Treatment is aimed at relieving the obstruction. For instance, if the obstruction causing sleep apnea is due to enlarged tonsils or adenoids, then these are surgically removed.
- Some children may undergo surgical reconstruction of the airway, uvulopalatopharyngeoplasty (UPPP).
- If the child is significantly obese, a weight loss regime will be the first course of treatment.
- Another treatment is a night time bilevel positive airway pressure (Bi-PAP) involving the delivery of airway pressure through a face mask at night while the child is asleep.
- Children with severe obstruction caused by poor muscle control or poor response to less invasive techniques may have to undergo a tracheostomy (as described above in stridor section).

*Figure 5*

## 6. Restrictive lung diseases

Children with cerebral palsy are most likely to develop spinal curvatures due to an imbalance in muscle tone like spasticity. Chest wall mobility is restricted due to chest wall deformity, kyphoscoliosis (abnormal curvature of the chest spine). This hinders the lung expansion and reduces lung function. These factors together make breathing laborious and may lead to respiratory failure. In a developing child the spinal curvature may continue to progress even if the physical growth has ceased. It is advised that these children wear thoracolumbar spinal supports and spinal surgery can be considered if kyphoscoliosis is progressing.

## 7. Chronic lung diseases of infancy

Chronic lung disease occurs due to problems in the baby's lungs and is common in premature babies born before 26 weeks and in babies with low birth weight. The premature lungs are not fully developed leading to chronic lung disease as a result of:

- Injury to lungs due to ventilator support, as many new born babies may require due to respiratory distress syndrome and forced ventilator breathing and high oxygen levels can damage baby's lungs.
- Many babies are born with fluid in their lungs or they may develop it.
- Infections
- Inherited problems can affect lung development
- Breathing meconium (intra-uterine fecal material) during delivery in lungs, causing inflammation and damage to lung tissue.
- Lack of nourishment.

## Conclusion

Breathing problems pose a significant threat to children with CP. It affects their cognitive, physical and overall growth and development. Thus, it is imperative to take cognizance at the very onset of the symptoms. Parents and caregivers should be well informed about the various respiratory issues that may arise with their child. They should avail medical advice from the doctors at the earliest to prevent complications. Home respiratory care techniques should be learnt to minimize the patient's discomfort. A multidisciplinary approach which includes medical, nursing, rehabilitation and home care will achieve the best results. Every effort should be made to maintain oxygenation and improve respiratory health to enhance the child's quality of life.

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## 13. Gastrointestinal Difficulties

For healthy growth and development of a child a good gastrointestinal (GI) tract functioning is essential. The children with CP may have various GI problems due to low muscle tone, reduced bowel motility, swallowing difficulty, spasticity, etc. Even if the parents are feeding nutritious food the child CP may still have nutritional deficiencies because of inherent GI problems. It is important to pick up early symptoms of GI problems to avoid complications of poor nourishment. Your pediatrician and dietician can help in identifying and educating you about different ways to manage GI problems. If the problems are ignored then complications like anemia, weak bones, low body weight and overall poor development may occur. The commonly observed symptoms are constipation, swallowing difficulty (dysphagia), acidity (gastroesophageal reflux disorder or GERD), abdominal pain, bloating of stomach and malnutrition. All these symptoms make the child irritable and moody, especially if the child is unable to speak or communicate. Below we describe the common GI symptoms associated with CP and ways to treat them.

### **Chewing difficulty**

Children with CP experience difficulty in chewing due to abnormal tongue movement, restricted jaw movement, lack in coordination of movements, spasticity (muscle tightness) and weak muscles. So the child is unable to eat solid food e.g. chapattis, biscuits, fruits, etc. The child may have frequent tongue bites. Insufficient quantity of food intake will cause nutritional deficiencies.

#### ***Treatment options:***

- Solid foods have to be smashed or pureed to feed the child.
- Medicines e.g. anti spasticity drugs may be helpful to reduce muscle tightness which facilitate jaw movements and therefore chewing.
- Oromotor exercises – a speech therapist can teach the parents oromotor exercises which will strengthen the muscles of the tongue, lips, mouth and improve coordination of movements. Oromotor therapy also involves teaching the child proper techniques of chewing different kinds of food.

### **Swallowing difficulty (Dysphagia):**

Difficulty in swallowing or dysphagia is a condition in which muscles used for

swallowing are weakened. Some children with cerebral palsy may be completely unable to swallow or may find it difficult to swallow liquids, foods or saliva.

***Causes of swallowing difficulty:***

- Weak tongue or cheek muscles make it difficult for food particles to move,
- Large food particles may enter the throat or may even block the airways,
- Weak swallow reflex (process which safely allows the food particles to move through the pharynx or food pipe.)
- Difficulty in initiating muscle movement to allow food to move from the mouth to the throat and then stomach.

***Diagnosis:***

Pediatricians, physicians or speech therapists who address swallowing disorders use a variety of tests like fiber optic laryngoscope, ultrasound or video fluoroscopy to analyze the swallowing mechanism and find the exact cause. Once the cause is identified specific treatment can be chosen.

***Treatment options:***

- Choose proper consistency of the food – if the child has difficulty in swallowing liquids then avoid them and thicken their consistency by adding flour, cereal or thickening agents. If the child has difficulty swallowing solids, then mash or puree them before feeding. Crush large solid particles into smaller pieces. Semi solid consistency is preferable.
- Medicines – drugs e.g. metaclopramide may help GI motility and improve swallowing.
- Oromotor exercises – Speech and swallow therapists will evaluate your child's swallowing difficulties and plan an exercise program to facilitate swallowing. Parents can learn different techniques to feed the child various types of food.

**Frequent burping or gas trouble**

These symptoms arise because of decreased motility in the GI tract or increased acid production or incomplete digestion of food. Medicines improving GI motility, antacids may reduce these symptoms. Physical exercises can improve muscle tone of the abdomen which can also prevent or alleviate these symptoms.

**Reflux (Gastroesophageal reflux disorder or acidity or GERD)**

Usually when food is swallowed, it travels down a tube in the body called the esophagus and then enters the stomach. A muscle called the lower esophageal sphincter, present at the end of the esophagus acts as a one-way valve and prevents food from coming back up the esophagus. This muscle is not developed in many newborn babies leading to what is called "spitting up". As the child grows, the sphincter develops, gets stronger and eventually stops food from coming up into the esophagus. Hence,

by the age of 1 to 1 ½ years, this problem of “spitting up” has stopped. However, many children with cerebral palsy continue to experience this problem, which is known as gastroesophageal reflux or GERD. GERD can cause inflammation of the esophagus called esophagitis, which causes pain, sometimes to the point where the child refuses to eat. This inflammation occurs due to acid (which is normally present in our stomach) coming up along with food. When severe, this condition can result in loss of blood, as well as narrowing of the esophagus (strictures), caused by chemical burns from the stomach acid.

### *Signs and symptoms:*

- Spitting up
- Burps
- Heartburn
- Stomach ache
- Bloating of stomach
- Irritability
- Decreased food intake

### *Diagnosis:*

- A contrast study of the gastrointestinal (GI) tract can be used to evaluate causes of GERD. In this study, the child drinks a milklike substance called barium and, through an x-ray, the radiologist monitors it as it goes down the stomach. This x-ray analyzes the anatomy of the GI tract to make sure there are no narrowed areas (strictures) or twists that may be causing the reflux. This study lasts for only about 15 minutes and is likely to miss reflux. Hence, even if this test is normal and the physician still strongly suspects reflux, other tests may be recommended, which include a gastric emptying scan and a pH probe study.
- A gastric emptying scan or a GE scan, sometimes also called a milk scan, is an investigation done in the nuclear medicine department. This technique lasts for an hour and assesses how well the stomach empties. The child is given a specific amount of formula or milk which contains an isotope. The radiologist then calculates the speed at which the stomach empties and also makes a note of any episodes of reflux. Ordinarily, children should empty at least half of the amount they drink over the span of one hour. Less than half indicates a delay in the emptying of the stomach, which can make reflux worse.
- A pH probe is a thin wire coated with plastic that is passed through the nose and into the esophagus (like a nasogastric tube), by a radiologist or by a gastroenterologist through a method called upper endoscopy (EGD). It remains a few centimeters above the lower esophageal sphincter and does not go all the way down to the stomach. The probe stays in place for 16 to 18 hours. During this time, the child is fed as usual or with apple juice, and the probe measures

each time the child has an episode of reflux and acid comes back up into the esophagus. If the child is already on acidity regulating medications, then these medications need to be stopped at least 5 days before the pH probe study can be done.

### ***Treatment options:***

- Among the several ways to deal with reflux episodes, a common method is to hold the child upright for 20 to 30 minutes after feedings.
- Another useful method is to avoid placing the child in an infant seat while feeding, as this often makes the child bend forward and puts pressure on the stomach, making the reflux worse.
- Using cereal or thickening agents to thicken the consistency of food can help in keeping the food in the stomach.
- Medicines - antacids reduce acid production in the stomach which prevents reflux. It also decreases the inflammation in the esophagus caused by reflux.
- Surgery – There are various surgical techniques where the lower esophageal sphincter is tightened to treat reflux. But these are invasive methods which are associated with several procedural complications and are used only if other non invasive methods have not resolved the reflux.
- Exercises – Abdominal muscle strengthening exercises and breathing exercises which will strengthen the diaphragm (muscle which is involved in keeping the lower esophagus closed) may help to prevent reflux.

## **Constipation**

Constipation is decreased frequency of passage of stools. Though constipation is a common problem in any child, it is more common in children with cerebral palsy, especially among those who either are unable to take sufficient liquids or are confined to bed or both.

### ***Signs:***

- Abdominal pain
- Bloating of stomach
- Irritability and crying
- Reduced food intake
- Irregular bowel movements

### ***Diagnosis:***

- It is essential to assess how constipated the child is by taking an abdominal x-ray, obtaining a careful history and performing a rectal exam.
- In severe cases or to rule out other causes of constipation your doctor may perform barium studies or a colonoscopy.

***Treatment options:***

- It is easier to prevent constipation than to treat it and the first step towards doing either of these is generally changes in diet. An increase in the intake of fluids and fiber in the diet should be helpful in preventing or treating mild constipation.
- In case of moderate amount of retained stool, changes in the diet alone may not be sufficient. The child will most likely need a “clean out”, if he/she has been experiencing fecal soiling, has not had bowel movement in a week or has been constipated for a long time. This is done to rid the entire colon of stool before having success with a maintenance regimen. A clean out can be done either “from above” with an infusion of a medication called Go-Lytely via a tube inserted through the child’s nose into the stomach or “from below” with enemas.
- Since children with cerebral palsy may suffer from decreased muscle tone, and because the colon also has muscles, it too may have reduced tone. Hence, the colon may not be able to contract effectively to expel the stool from the rectum. In such cases, children may need a stimulant such as bisacodyl or senna to help with these contractions.
- To pass stools the child also has to contract abdominal muscles. In CP these muscles may be weak and therefore, contribute towards constipation.
- Medicines – Stool softeners, rectal suppositories, enemas may be given to relieve constipation. Talk to your doctor regarding appropriate medicines for your child.
- Exercises – Regular rehab therapy will assist in strengthening the abdominal muscles and to improve GI motility.
- Dietary advice – A dietician can help you to plan a diet chart which includes food types to prevent constipation and maintain good bowel health.

**Diarrhea**

This may indicate infection in the bowel or if it is chronic then it may also be due to inflammatory bowel disease. Infection can be viral or bacterial. Lot of liquid intake is required to prevent dehydration. Chronic diarrhea can lead to nutritional deficiencies.

***Treatment options:***

- Increased fluid intake – ORS, electrolyte powder, etc.
- Probiotic medicines may help to reduce diarrhea by acting on gut flora.
- Antibiotics are required in cases of bacterial infections.
- Digestive enzymes to aid in digestion
- Nutritional supplements will be helpful in chronic cases.

**Abdominal pain**



There are numerous reasons for abdominal pain. All the above described conditions may present with abdominal pain. It is important to identify the underlying cause for proper treatment. So take your child to your doctor at the earliest in case of persistent or recurrent abdominal pain. The specific treatment will depend on the exact reason of the pain.

## **Vomiting**

Vomiting is “throwing up” of improperly digested food. There are many reasons for vomiting e.g. reflux, indigestion, reduced GI motility, infection, etc. Medicines can be prescribed to stop vomiting but at the same time it is important to find the underlying cause. One should seek medical advice in case of frequent vomiting episodes.

## **Poor nutrition**

Poor nourishment is very common in children with CP due to all these above associated GI problems. Anemia (low hemoglobin), low calcium, vitamin and mineral deficiencies (A, B complex, C, D, E, zinc, magnesium, etc), low body weight and height are commonly seen in these children. This affects their overall growth and development. So these issues should be addressed at the earliest and maximum efforts should be made to prevent them. Nutritional supplements will help to treat or prevent deficiencies and complications. Good nutritious healthy food items should be incorporated in the child’s diet with the help of a dietician.

## **Conclusion**

The groundwork of all happiness is good food and a healthy gut. Children with CP face many GI problems which affect their overall wellbeing. They have specific dietary requirements. Parents have to make extra efforts to educate themselves about various ways to meet their child’s dietary challenges. A team of specialists including your pediatrician, dietician and therapists can make this challenging task easier for the parents. A comprehensive diet plan including supplements will enhance nutritional value of the meals.

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## 14. Cognitive Impairments

Cognition or the ability to use one's intellectual capacity to accurately perceive, reason and learn, tells us about many aspects of our lives. However, as cerebral palsy is essentially caused by damage to the brain, the centers that transmit accurate information from several sources may be impaired. This means that a person with brain injury may experience difficulty in understanding or processing the information he or she receives. When this occurs, it's referred to as cognitive or intellectual impairment. The extent and nature of brain injury in cerebral palsy can lead to lack of muscle control, difficulty in motor coordination and cognitive impairments. Children with cerebral palsy are also at an increased risk of developing emotional and behaviour problems.

Preschoolers with cerebral palsy are unable to explore the world around them due to their physical limitations and they end up spending more time passively unengaged as compared to other preschoolers. By school age, social contact is further reduced as majority of their free playing time is used up by undergoing different forms of therapies. As these children move on to adolescence, they may develop feelings of learned helplessness and may feel socially isolated, which could in turn lead to increased dependence. They would want their activities to be planned by adults rather than seeking spontaneous activities with peers. As adults, individuals with cerebral palsy have restricted involvement due to their physical limitation; it can lead to the development of physical, medical, cognitive, emotional, or psycho-social secondary conditions with adverse outcomes in health, wellness, and quality of life which has been discussed in detail below:

### **What causes cognitive impairment?**

There is no single cause for cognitive impairment in children however; the brain injury that caused cerebral palsy is likely to be the cause of cognitive impairment. The extent and the nature of the impairment are dependent on where the brain injury occurred, and its severity.

More specifically, cognitive impairment can be attributed to conditions that occur in the fetal stages of development, or at birth. However, sometimes, the causal factors are unknown.

Some of the conditions or circumstances that cause cognitive impairments include:

- Chromosomal abnormalities

- Genetic abnormalities
- Pre-natal infections
- Preterm complications
- Lack of oxygen during labor
- Brain hemorrhage
- Stroke

Roughly about one - fourth of children with cerebral palsy may experience specific learning difficulties which may include short attention span, motor planning difficulties, perceptual difficulties and language difficulties. The more severe the brain damage, the greater is the risk of cognitive impairments. It has been seen that individuals with spastic quadriplegia have about a 50 percent chances of mental retardation. However, it is not necessary that if a child has cerebral palsy, he or she has impaired cognitive functioning. Sometimes, a child's cerebral palsy will only affect his or her physical and not cognitive functioning.

Like many other aspects of having a child with cerebral palsy, cognitive impairment requires management. Studies reveal that individuals with cerebral palsy who are struggling with cognitive impairment have more general health concerns, and higher mortality rate.

As parents you would be worried that your child's full potential may not be realized. However, children with cognitive impairments can also lead enjoyable and meaningful lives.

Some of the brain's functions that fall under cognition include:

- Attention span and concentration
- Recognition
- Comprehension
  - Decision-making
  - Problem-solving
  - Learning
  - Memory
  - Difficulty processing emotions and feelings
  - Language skills
  - Speech proficiency

Currently, it has been estimated that around 65 percent of the individuals living with cerebral palsy also have some form of mental retardation. About 50% are full mentally retarded i.e. an IQ which falls below 70. Learning disabilities may be present, depending on the area of the brain that was damaged. About a third of individuals with cerebral palsy have mild intellectual impairments, a third have moderate – to - severe intellectual impairments, and another third have normal intellectual functioning.

## **How would you know if your child is struggling with cognitive impairment?**

The key to determining if your child has a cognitive impairment is to observe him or her in the home environment.

- Is a child in his own world and unresponsive?
- Does he or she seem uninterested in the people or activities within the home?

Children should respond to external stimulation's such as noises, the sound other mother or father's voice, or a touch. If a child is not responsive under those conditions, he should consult a pediatrician immediately.

Some of the signs that a child has a cognitive impairment include:

- Inability to recognize noises
- Delayed speech or language development
- Difficulty learning
- Shortened memory span
- Depression or anxiety
- Difficulty in maintaining attention and concentration
- Difficulty to express thoughts quickly and process information
- Difficulty in maintaining social interaction
- Displaying temper tantrums

As a parent it's important for you to find out about the cognitive impairment that your child has as this can lead to early intervention and a better prognosis.

## **Emotional and Behavioural Problems:**

About two thirds individuals with cerebral palsy suffer from severe emotional stress. Individuals with cerebral palsy may display behavioural problems or emotional issues which in turn, may affect their overall psychological development and ability to have social interaction.

## **Communication difficulties:**

Lack of ability to communicate efficiently can lead to disturbances associated with behavioural problems. During such situations the children call for a lot of physical and mental stress to the parents. Excessive attention should be discouraged whereas the child should be kept involved by talking or just maintaining eye contact.

## **Frustration:**

Individuals with cerebral palsy may face difficulty in completing a task due to either their physical or cognitive limitation which may lead to getting angry and discouraged about their condition. Repetitive failures and not being able to vent out their feelings can lead to frustration. This problem can be overcome by helping them with the task

and finishing it which would foster a sense of achievement.

**Anxiety:**

As adults with cerebral palsy may age they may develop age related issues like arthritis, bone fractures, chronic pain and fatigue. Due to these additional problems they may develop anxiety about their worsening condition and how their condition can limit their functioning. Individuals may also develop sleep problems which in turn can contribute to anxiety and other emotional problems.

**Low Self- esteem:**

Due to perceived physical limitations, loss of body control and medical condition, individuals with cerebral palsy may suffer from low self-esteem. As a parent you would be protective about your children however this could lead to dependence and low self -worth.

**Depression:**

Children and adults suffering from cerebral palsy may not be able to control their body, be embarrassed about their body in social situations, may have poor levels of achievement and confidence. They would have a very negative view of the future and in turn could lead to depression. However, it is seen that it may not be so much due to the severity of the disability but it would depend on how well they cope with the disability.

**Psychosocial Factors:**

The development of both intelligence and personality relies heavily on developmental experiences and the opportunity for self-expression. As physical limitations can lead to poor social exposure and interaction, the child may find it easier to withdraw towards social isolation.

**Psychological Testing:**

Children with cerebral palsy might find it difficult to respond to the tests that are timed or that require manipulation of objects due to physical limitation such as some of the sub tests of Wechsler Intelligence Scale. However, alternative tests such as Pictorial Test of Intelligence, the Columbia Mental Maturity Scale or the Peabody Picture Vocabulary Test are recommended. There are various tests to measure gross motor functioning of individuals with cerebral palsy like Bruininks - Oseretsky Test of Motor Proficiency, the McClenaghan and Gallahue Checklist and the Vulpe Assessment Battery. A test which is very fast and easy-to-administer is the Raven's Coloured Progressive Matrices through which very valuable data about the individual's linguistic ability, visuo- perceptual, and memory functioning can be derived. This test can be administered despite their motor and speech disorders.

## 15. Nutritional Deficit

Research indicates that 40 – 60 % of growing children with cerebral palsy are undernourished and/or malnourished. Individuals with CP frequently have feeding and swallowing problems that may lead to poor nutritional status, growth failure/ linear growth/ low weight for stature, chronic aspiration, esophagitis and respiratory infections.

Across the cerebral palsy spectrum, poor nutritional status is caused by distinct pathways ranging from following:

- a. Inadequate intake/ oral dysphagia/ oral-pharyngeal dysphagia( Oro-motor difficulties):* These include tongue thrust, poor lip closure and inadequate tongue movements to manipulate food around the mouth. These difficulties cause food and drink to spill from the mouth, resulting in loss of calories and hydration. A modified consistency diet (eg: soft, minced & moist, or pureed), is thus required.
- b. Gastro esophageal reflux (GER) & Constipation:* They are the most common physical symptoms. GER is due to poor muscle tone that affects the ability to push stool through the colon and of the lower esophageal sphincter, which causes the stomach's contents to wash back up into the esophagus causing acid reflux. Poor oral fluid intake and poor fiber intake causes constipation.
- c. Sensory difficulties & Behavioral etiologies:* Children with CP can have sensory difficulties that make feeding difficult. They may be overly sensitive to touch in and around the mouth and face. The child may find the touch of food, bottle teat, a spoon or even a hand unpleasant. This may cause the child to bite down, turn away, refuse to open the mouth or even gagging or vomiting.
- d. Chronic aspiration / chronic pulmonary disease:* Some children with oro motor difficulties and gastro esophageal reflux are at risk for recurrent aspiration, which can lead to pulmonary disease.
- e. Self feeding:* These children are unable to feed themselves and may require extensive use of assisted technology and are dependent on others to feed them. Caregiver burden is a significant concern as the feeding process may require considerable time and may be associated with stress and fatigue which in turn

affects the feeding process. The best foods to serve are those that are easiest to feed, while still providing adequate nutrition. Smaller meals spread throughout the day often are less exhausting for the patient and/or caregivers as compared to three meals a day. It may be found that after 30 – 40 minutes of eating and drinking, children become so fatigued that beyond this time negligible amounts of food are consumed.

- f. **Nutritional deficiency:** Medications commonly used with cerebral palsy lead to a decrease in availability of vitamin D and K, as well as decreased levels of calcium, magnesium, folic acid, vitamin B6, Vitamin B12 and C. They therefore run a high risk of developing osteopenia/osteoporosis. Additional supplementation would thus be required. Some studies have shown that children with cerebral palsy often eat enough to meet their energy needs, but not their nutrient needs, which results in a low level of fat free mass.
- g. **Tooth decay:** Lengthy and prolonged bottle feedings of milk and juice promote the decay of the primary upper front teeth and molars.

### **Feeding issues: presentation of food to the mouth**

Dysphagia (difficulty swallowing) often accompanies neurologic disease. Symptoms include drooling, choking or coughing during or following meals; inability to suck from a straw; a gurgly voice quality; holding pockets of food in the buccal recesses (of which child may be unaware); absent gag reflex; and chronic upper respiratory infections. Proper positioning for effective swallowing should be encouraged (i.e., sitting bolt upright with the head in a chin down position)

Swallowing liquids of thin consistency such as juice or water requires the most coordination and control. Liquids are easily aspirated into the lungs and may pose a life threatening event. If a child has difficulty consuming thin liquids, fluid requirements may be met by thickening liquids. E.g. cornstarch and dry milk powder.

Poor nutritional status, altered growth or growth failure, inadequate energy provided, inadequate fluid intake, drug nutrient interaction problem, constipation and feeding problems are usual problems identified in child with CP.

## 16. Dental Issues

*Contributed By: Dr. Fardin Adhikari*

No intraoral anomalies are unique to persons with cerebral palsy. However, several conditions are more common or more severe than in the general population.

**Periodontal Disease** is common in people with cerebral palsy due to poor oral hygiene and complications of oral habits, physical abilities, and malocclusion. Often the patient will not be physically able to brush or floss adequately. Another factor is the gingival hyperplasia caused by medications.

**Dental Caries** is prevalent among people with cerebral palsy, primarily because of inadequate oral hygiene, tendency towards soft food high in carbohydrates due to difficulty in chewing.

- Caution patients or their caregivers about medicines that reduce saliva or contain sugar. Suggest that patients drink water often, take sugar-free medicines when available, and rinse with water after taking any medicine.
- Advise caregivers to offer alternatives to cariogenic foods and beverages as incentives or rewards.
- For people who pouch food, talk to caregivers about inspecting the mouth after each meal or dose of medicine. Remove food or medicine from the mouth by rinsing with water, sweeping the mouth with a finger wrapped in gauze, or using a disposable foam applicator swab.
- Recommend preventive measures such as fluorides and sealants.

**Malocclusion** in people with cerebral palsy is approximately twice than in general population, primarily due to disharmonious relationship between intraoral and extraoral muscles.

**Dysphagia**, difficulty with swallowing, is often a problem in people with cerebral palsy. Food may stay in the mouth longer than usual, increasing the risk for caries. Additionally, the semi-soft foods caregivers may prepare for people with this problem tend to adhere to the teeth.

Advise the caregiver to inspect the patient's mouth after eating and remove any residual food.

**Drooling** affects daily oral care as well as social interaction.



**Bruxism** is common in people with cerebral palsy, especially those with severe forms of the disorder. Bruxism can be intense and persistent and cause the teeth to wear prematurely.

**Trauma And Injury** To the mouth from falls or accidents occur in people with cerebral palsy, particularly to the upper front teeth.

## **Preventive Dental Management**

The intraoral conditions affecting a person with cerebral palsy are not unique to those affecting the general population; however they are more common and severe due to inability to maintain a good oral hygiene.

It is rightly said that “*Prevention is better than Cure*”

We need to follow few basic steps in order to give them a healthy living free of the second most severe type of pain known to mankind: the *Dental Pain/Toothache*.

### ***Basic Preventive Methods:***

Beginning early is best for your child when it comes to dental care. Details are offered on several ways to proceed and useful interventions for special situations.

Start oral hygiene in the first year even before the child has teeth. Begin by just wiping the inside of the child’s mouth with a moist cloth – this will get him used to having his mouth cleaned. Tooth brushing should start by age 6 months and can be initiated with soft brushes. Brushing should include the gums and tongue as well as the teeth.

The first visit to the dentist should be between the ages of 6 and 12 months. At this time, the dentist will review the oral hygiene program you are using and will help you resolve any difficulties. Usually x-rays will not be taken until later, but the main goal of the first visit is for the dentist to understand how your child will react in the dental office and what his special needs are.

Tooth brushing is the most important daily activity in maintaining oral hygiene, and it needs to be established early. Brushing should not be a struggle for the parent or the child. Find a time of day when your child is usually in a good mood, and try to do it at the same time every day. Then you can provide some reward for the child’s behaving well. Eventually, brushing becomes an accepted part of the daily routine. Although it is advisable to leave the child with a clean mouth overnight, brushing when the child tolerates it best will provide the greatest opportunity for success in the long run.

If your child has problems of head and trunk control, you need to position him so that you can control his posture. This is usually done in the best seating system the child has, such as his wheelchair. Choose a soft mutilated nylon brush and use both circular and up-and-down motions. If the child will not tolerate a toothbrush, use a cotton-tipped swab or a soft washcloth that has been soaked with mild abrasive

toothpaste or with an antiseptic solution. Eliminate gagging by watching where you are brushing and avoiding areas that trigger the gagging.

Children with CP may be more susceptible to tooth decay than their non-disabled peers. This is because the natural, self-cleaning which is facilitated by saliva (especially at night) may be disrupted. In addition, debris which usually gets moved away by the motion of the tongue may not be cleared so effectively if a child's tongue is less mobile.

Regular brushing of teeth is vital. You should start to clean your baby's teeth as soon as they appear in the mouth. When brushing your child's teeth try to develop a technique which is three teeth at a time in a circular or 'mini-scrub' motion. Pay particular attention to the inner surfaces and the small, difficult-to-clean spaces between the teeth and the biting surfaces of the teeth at the back of the mouth. Using a battery operated toothbrush might help to make teeth clean easier.

Dental treatment can be very distressing for a young child. . In some areas there are pediatric dentists who are trained in special needs. Ask your consultant, your GP or your regular dentist for advice on this.

Once the child starts to develop teeth, this process can be carried out with a small toothbrush. If a baby's rubber toothbrush is available, many young children will enjoy munching on this. This may also provide a good practice for developing chewing skills. If the child finds it too difficult to tolerate a toothbrush, then it is preferable to continue tooth-cleaning with a finger, and with the possible introduction of a small amount of toothpaste.

When your child is young, you may find it simplest to clean his teeth while he is lying across your lap on his back. This makes it easier to keep him still, and also gives you a better view of his mouth. Usually it is enough to clean your child's teeth thoroughly once a day – preferably in the evening so your child does not go to bed with food particles on his teeth.

A hazard you should know about if your child is still nursing is the "nursing bottle syndrome." Nursing bottle syndrome refers to the very early rapid decay of teeth that sometimes occurs when children are given a bottle at bed- or nap-time. To avoid this problem, never let your child fall asleep with a bottle in his mouth.

Once your child has the motor skills to begin brushing his own teeth, you may need to get him a toothbrush with an adapted handle to help him maintain his grasp. Remember, too, that electric toothbrushes can provide some of the finer movements your child cannot do himself.

If your child can walk to the bathroom, allow her to brush her own teeth. If not, you will need a spit cup or emesis basin so she can spit out the contents of her mouth after she brushes her teeth in bed.

## Follow These Steps

### *Getting Started*

**Location.** The bathroom isn't the only place to brush someone's teeth. For example, the kitchen or dining room may be more comfortable. Instead of standing next to a bathroom sink, allow the person to sit at a table. Place the toothbrush, toothpaste, floss, and a bowl and glass of water on the table within easy reach.

No matter what location you choose, make sure you have good light. You can't help someone brush unless you can see inside that person's mouth. Positioning your body lists ideas on how to sit or stand when you help someone brush and floss.

**Behaviour.** Problem behaviour can make dental care difficult. Try these ideas and see what works for you.

At first, dental care can be frightening to some people. Try the "tell-show-do" approach to deal with this natural reaction. **Tell** your client about each step before you do it. For example, explain how you'll help him or her brush and what it feels like. **Show** how you're going to do each step before you do it. Also, it might help to let your client hold and feel the toothbrush and floss. **Do** the steps in the same way that you've explained them.

### *Three Steps to a Healthy Mouth*

Like everyone else, people with developmental disabilities can have a healthy mouth if these three steps are followed:

1. Brush every day.
2. Floss every day.
3. Visit a dentist regularly.

#### *Step 1: Brush Every Day*

- Use a pea-size amount of toothpaste with fluoride, or none at all. Brush the front, back, and top of each tooth. Gently brush back and forth in short strokes.
- Help the person rinse with plain water. Give people who can't rinse a drink of water or consider sweeping the mouth with a finger wrapped in gauze.



Figure 1 : Angle the brush at the gumline and brush gently.

Get a new toothbrush with soft bristles every 3 months, after a contagious illness, or when the bristles are worn.

### **Make the toothbrush easier to hold.**



*Figure 2: The same kind of Velcro® strap used to hold food utensils is helpful for some people.*



*Figure 3: Others attach the brush to the hand with a wide elastic or rubber band. Make sure the band isn't too tight.*

### **Make the toothbrush handle bigger**

You can buy a toothbrush with a large handle, or you can slide a bicycle grip onto the handle. Try other toothbrush options. A power toothbrush may make brushing easier.



*Figure 4: You can also cut a small slit in the side of a tennis ball and slide it onto the handle of the toothbrush.*

### **Step 2: Floss Every Day**

Flossing cleans between the teeth where a toothbrush can't reach. Many people with disabilities need a caregiver to help them floss. Flossing is a tough job that takes a lot of practice.

### **Positioning Your Body: Where to Sit or Stand**

Keeping people safe when you clean their mouth is important. Experts in providing dental care for people with developmental disabilities recommend the following positions for caregivers. If you work in a group home or related facility, get permission from your supervisor before trying any of these positions.



*Figure 5: If the person you're helping is in a wheelchair, sit behind it. Lock the wheels, then tilt the chair into your lap.*



*Figure 6: Stand behind the person or lean against a wall for additional support. Use your arm to hold the person's head gently against your body.*

***Step 3: Visit a Dentist Regularly***

Your child should have regular dental appointments. Professional cleanings are just as important as brushing and flossing every day. Regular examinations can identify problems before they cause unnecessary pain.

As is the case with dental care at home, it may take time for the person you care for to become comfortable at the dental office.

A “get acquainted” visit with no treatment provided might help: The person can meet the dental team, sit in the dental chair if he or she wishes, and receive instructions on how to brush and floss. Such a visit can go a long way toward making dental appointments easier.

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## 17. Sleep Disturbances

*Contributed By:* **Dr. Shekhar Patil**

Approximately 50% of children with cerebral palsy can have difficulty in getting sleep or staying asleep. Additional problems such as reflux, epilepsy can make things even more difficult. Even if they fall asleep, they may have difficulty in maintaining sleep state through the night. Infants and toddlers can have altered sleep cycle, sleeping during the day and waking up at night. Sleep deprivation in children with additional needs can be equally distressing to the child as much as to the parent. Some children with spasticity may have a difficult time because of the muscle spasms. Children with dyskinetic cerebral palsy tend to move a lot in the bed and this may interfere with falling asleep.

### **Causes of Sleep disturbances:**

- Fluctuating and or extreme temperature, too warm or too cold
- Hunger / Thirst
- Incontinent
- Sickness
- Pain
- Ambient noise
- Overstimulated before bedtime
- Overstimulating environment of the bedroom
- Difficulty breathing (enlarged tonsils, adenoids, recurrent colds)
- Excess of daytime naps

### **Management of Sleep Disturbances**

- Keep a strict diary for two weeks and note the bed-time and the actual sleep time. Make a note of the ambient sound. Note the frequent awakenings if any.
- Make a note of the daytime naps.

- Create a conducive environment to sleep. Keep it dark and quiet. Ensure that there is no TV or laptops or desktops in the room
- Ensure a fixed sleep time
- Next morning wake them up at a regular and fixed time
- Keep room temperature comfortable (approx 20 - 24<sup>0</sup> C)
- Your child should not go to bed hungry, ensure proper meals before the night sleep.
- Avoid over excitement and excessive physical activities before sleep
- Cut down on afternoon naps
- Use help of your doctor to correct the sleep cycle
- Sometimes your doctor may prescribe certain medications like melatonin, clonazepam for regularisation of the sleep pattern and irritability
- Seek help for pain and sickness

## **SECTION C:**

# **Rehabilitation**





## 18. Physiotherapy

Physiotherapy plays an important role in managing a child with cerebral palsy as soon as the child is diagnosed. Depending on the symptoms, the physical therapy program is planned for every child uniquely. Children with mild cp may not need intervention as extensive as for a child with moderate to severe cp. Physiotherapy helps to improve independence by improving mobility, strengthening the muscles , improve the ability to move the parts of the body, prevent joints to become tight or contractures to develop. Exercises help the child to learn how to sit, stand and walk

### **Physiotherapy goals differ with the different types of CP:**

#### **1. Spastic child :**

Relax stiff muscles

Prevent deformities

Encourage movements which prevent spastic body positions

#### **2. Floppy child :**

Provide support in good position

Strengthen muscles.

#### **3. Ataxic child :**

Improve balance

Help walk and stand steady

Control unsteady movements

#### **4. Athetoid / dyskinetic child :**

To control the abnormal or unwanted movements.

Control of abnormal posture.

Improve co-ordination

Smooth execution of voluntary movements.

**Physiotherapy treatment aims to:**

- Encourage normal movement as much as possible.
- Follow developmental stages.
- Encourage use of both sides of body.
- Improve posture: to maintain correct position while sitting, standing and walking.
- Strengthen muscles: improve the power of the weak muscles.
- Improve range of motion of all the joints i.e. to prevent the joints to develop tightness.
- Exercises to reduce tightness and prevent contractures: due to complications like spasticity and dystonia, these children tend to develop contractures, which can be prevented by corrective exercises and medical management.
- Exercises to improve endurance.
- Chest physiotherapy to reduce secretions to help keep lungs clear and strengthen respiratory muscles
- Improve balance in both sitting and standing
- Teach or develop transitions, example : supine/lying to get up, sit to stand, half kneel to stand etc.
- Teach usage of adaptive devices.

Physiotherapist can guide the parents well as they spend a lot of time with the child. Parents need to get trained, so that home program can be followed effectively. Therapist and parents need to work as a team to obtain the best result in the child. There are several centers where different types of therapies are offered for cerebral palsy. Knowledge about these different therapies will help the parents to carry out exercises of home program.

Different therapies used by therapist to treat children with cerebral palsy are:

1. **NDT (neurodevelopment therapy):** it is a therapeutic approach, which helps in assessment and management of movement problems or dysfunction in children with neurological dysfunction. It aims to maximize child's functional capabilities. It is also known as bobath therapy and was developed in 1940's by Dr and Mrs. Bobath. The treatment aims to make desired movements more possible and prevent undesired movement. It also helps to achieve normal motor milestones in children with cerebral palsy.

2. **Patterning:** it is a concept based on the theory that typical brain development can be facilitated in the brain injured child by passively repeating the sequential steps of typical development. Failure to normally

complete one stage of development impairs the development of subsequent stage. This approach is laborious and also requires multiple sessions every day. Parents and caregivers are trained to carry the procedure at home also.

3. ***Constraint-induced therapy:*** this therapy aims to improve the use of affected hand in child with hemiplegia (paralysis of one side of the body). The normal hand is plastered for couple of days, to improve the use of affected hand.

4. ***Hippotherapy:*** it's a technique of horseback riding which has shown improvements in muscle tone, posture and balance.

5. ***Spider web therapy:*** this techniques involves a number of different elastic cords to specific points on one end of patient's body to different points on the other. This device helps to move the patient move independently while controlling their movement as well as strengthening different parts of the body.

### **Parents can use following simple approaches to do therapy at home:**

- Exercise the child's limbs using interactive play.
- Set aside times for active play including other members of the family.
- You can encourage your child to move and play by banging pots kept together or slapping hands on the table
- Child should be encouraged to play with others, especially with children of the same age.
- Encourage activities with the affected side more, for example if your child is hemiplegic, you can encourage him/her to watch TV from the affected side or by talking to them by standing towards their affected side.

Below are few simple physical therapy exercises/advice on various position or equipments including diagrams, to help parents or care givers continue therapy at home.

Home exercises which can be easily carried out by parents, illustrated with pictures:

### **A. Relaxation techniques**

#### ***A1. Relaxing child on lap:***

Lay your child on your lap and make sure that the arms are forward and not curled up under the body

- With your hands gently press the bottom.
- This technique helps to relax child's body, and is always a good exercise to start with.

### ***A2. Relaxing the child:***

Hold the child on their side with their back against your stomach.

Put one hand under the shoulder, one on the hips.

Hold the shoulders and slowly twist the lower part of the body away from and towards you.



*Figure A1*



*Figure A2.1*



*Figure A2.2*

### ***A3. Relaxing the body***

- Lay the child on your legs, keeping the body as symmetrical as possible that is, with the head in the Middle and slowly lift and lower the hips to help them relax.
- The legs will become more relaxed as you do this.
- This is a good exercise to relax your child before doing other exercises.



*Figure A3*

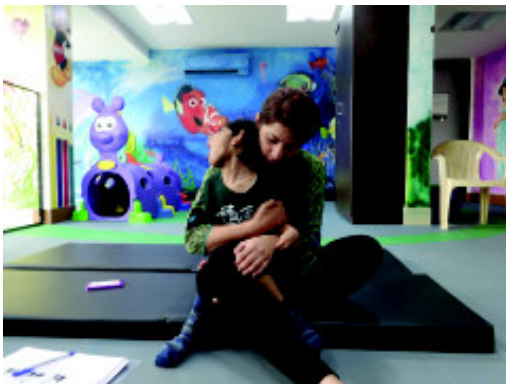
#### ***A.4 Relaxing on a Swiss/therapy ball (holding legs)***

- Keep the child's arms forward and place your hand on their legs to steady the child on the ball. Keep the legs apart.
- Gently stretch one leg out and then the other.
- Carry on until you feel child is relaxed.



*Figure A4*

#### ***A5 Relaxing in sitting position***



*Figure A5.1*



*Figure A5.2*

- Make your child sit on your lap facing away from you.
- Hold across the child's chest and under the shoulders with one arm and keep the hips steady with the other.
- Slowly twist body to one side and then the other.
- This will help relax the body and is a good exercise to do whenever your child feels stiff.

### **B. Lifting and Carrying**

#### ***B1. Carrying baby curled up***

- Carry your child in a curled up position.
- Support behind the neck and shoulders.
- This position helps to reduce extensor tone.



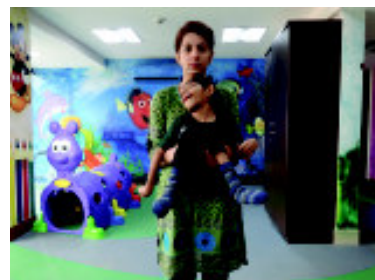
*Figure B1*

**B2. Carrying child from hips:***Figure B2.1**Figure B2.2*

- Carry your child, with their legs around your hips.
- Support them under their hip.

**B3. Carrying the child in aero plane position:***Figure B3.1**Figure B3.2*

- Carry the child with your arm between their legs & your hand under the chest.
- Keep their arms and legs turned out.

**B4 Carrying the child facing forward***Figure B3.1**Figure B3.2*



- Carry baby with their back against you, legs curled up.
- Support under the thighs
- Keep their legs apart.

### C. Prone activities:

#### *C.1 Lying on forearm:*

- Encourage your child to lie on their front to play and to take weight on their forearms.



*Figure C1.1*



*Figure C1.2*

#### *C.2 lying on prone to encourage head lifting:*



*Figure C2.1*



*Figure C2.2*

- Encourage your child to lie on their front.
- Roll up a towel/bolster to put under the chest if necessary. This keeps the arms forwards so that the weight is on the forearms.
- You can place a toy in front to encourage your child to lift up their head.



### ***C3 Encourage play by placing child on your lap straight arms)***

- Encourage your child to play in this position with their elbows straight.
- Later on they can be encouraged to put more weight on their hands and start to reach out.



*Figure C3.1*



*Figure C3.2*

### ***C4 Encourage Weight Shift Using Play***

- Encourage child to shift weight n take object.



*Figure C4.1*



*Figure C4.2*

### ***C5 Exercise to encourage forearm weight bearing***

- Encourage child to lie on forearm
- Encourage child to raise chest by taking weight on forearms



*Figure C5*

## C6 Exercise to Strengthen Back Muscles



Figure C6.1



Figure C6.2

- Ask child to lie on the back
- And ask the child to look up
- This exercise helps to strengthen the back.

## D. Rolling

### D.1 Rolling Holding Hips and Legs



Figure D1.1



Figure D1.2



Figure D1.3



Figure D1.4

- With the child lying on their back, practice rolling from side to side.
- Do this by placing your hand on the hip and slowly moving it so that your child is lying on their side.
- Do this to both sides and do it slowly so that your child can move with you.

## ***D2. Rolling using Child's arms***



*Figure D2.1*



*Figure D2.2*



*Figure D2.3*



*Figure D2.4*

- With your child lying on their back, hold their hands above their head with the elbows straight.
- Slowly bring one arm down and cross over the body, while keeping the other arm up.
- Use the top arm to guide them, encouraging the top leg to bend to help roll over.

## **E. Supine activities:**

### ***E1. Encouraging reaching for feet.***

- Encourage child to play with their own body
- This exercise increases child's awareness.



Figure E1



Figure E.2



Figure E3



Figure E.4

## **E2. Bridging exercise:**

- The child lies on their back.
- Bend both knees up and ask the child to lift up their back.

## **E3. Single leg bridging:**

- Lay the child on their back with one leg bent.
- Put one leg up on the other leg bend.
- Ask the child to lift up their bottom and hold this position for a few seconds.

## **E.4 Encouraging side lying position from supine**

- Lay the child on their side.
- To stop them rolling over onto their backs, you could place them against a sofa or large cushion.
- Place a pillow in between their legs to keep them apart.

## **F. Activities in kneeling:**

### **F1. Encouraging kneeling position:**

- Place child in the crawl position.



- Support their hips with your legs if required

### ***F2. Kneeling against object:***

- Encourage child to stay up on their knees, with the weight supported equally by both legs.
- Kneeling against a table is easier to start with.
- use of a swiss ball is good for developing balance.

### ***F3. Kneeling with rotation:***

- Encourage kneeling against a table
- Encourage child to rotate and reach for objects
- Encourage child to turn only upper body.

### ***F4. Supported half kneeling:***

- Hold child at the hips.
- Make sure their legs are apart.
- Encourage your child to keep their balance.



Figure F1



Figure F.2



Figure F3



Figure F4



Figure G1.1



Figure G1.2

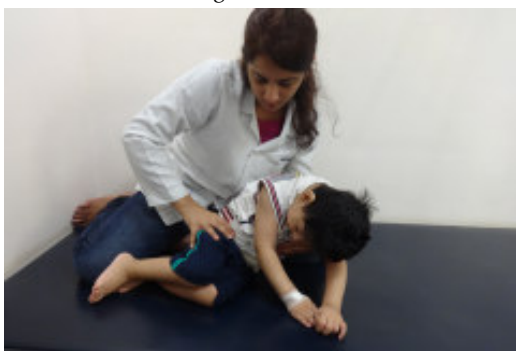


Figure G1.3



Figure G1.4



Figure G2



Figure G3



Figure G4.1

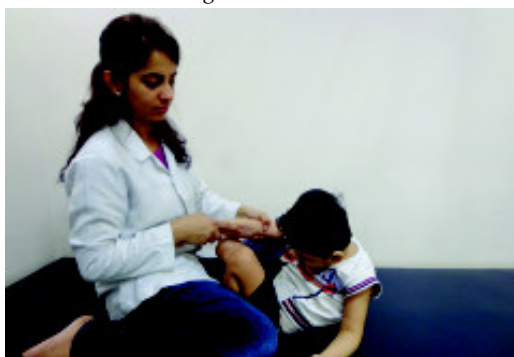


Figure G4.2

## **G. Moving From Lying Position To Sitting:**

### ***G1. Getting up from lying to sitting position: (fig G1.1, G1.2 ,G1.3,G1.4,)***

- Lay the child on their front in prone position.
- Bring the weight backwards over the knees by holding the child's hips.
- Encourage the child to push up with their hands.
- Move the child's hip slowly over to one side so the child is now sitting.

### ***G2. Getting up from lying to sitting to encourage head control***

- Place your hands behind your child's shoulders and gently support the head with your hands
- Make sure that they are facing you with their head in the middle.
- Bring the child slowly up to the sitting position.

### ***G3. Getting up from lying to sitting with controlling the hands, encouraging head control***

- From lying down bring child up to the sitting position by holding their hands.
- Make sure that their head is in the middle and encourage them to grasp your thumbs.
- Bring child slowly up to the sitting position, letting them do as much of the work as they can.
- You can help them to go down again in the same way.

### ***G4. Getting up from lying, encouraging weight bearing on one hand, to encourage head control***

- Bring child to sitting position from lying by holding one hand.
- Gently tilt them over to one side and let them push up with that hand.
- Do this as slowly as you can so that your child can do as much of the activity as possible.

## **H. Sitting activities:**

### ***H1. Encouraging head control when sitting:***

- Sit with your child on your lap facing you.
- Place your hands behind their head and shoulder.
- Encourage your child to look at you, encourage to Talk and play .

### ***H2. Encouraging activity in sitting position:***



Figure H1



Figure H2



Figure H3



Figure H4



Figure H5



Figure H6



Figure H7



Figure H8



- Encourage child to reach for toys to either side and to keep their balance.
- This exercise helps to improve sitting balance and strengthens stomach and back muscles.

### ***H3. Encourage activity sitting on stool/chair:***

- Encourage reaching forward

### ***H4. Side sitting:***

- Encourage your child to sit as shown.
- Make sure they are taking weight through the straight hand
- Encourage the child to use the other hand to reach for toys and to play.

### ***H5. Activity on bolster***

- Encourage child to do rotations
- Ask them to reach to object, encouraging reach outs
- This exercise improves reach outs

### ***H6. Exercises on Swiss ball***

- Make your child Sit on the ball, holding them at the hips.
- Gently bounce up and down.
- When this becomes easier, then slowly tilt them to one side and then to the other.
- You can also try tilting the hips backwards and forwards too.
- Encourage your child to keep their balance and keep as upright as possible and also give them reach out.

### ***H7. Sitting on CP chair:***

- Encourage child to sit on CP, in upright position.
- Make sure the hip and knee are in 90 degree position.
- The hands are well supported.
- The head also should be well supported, if the child has poor head and neck control.

### ***H8. Encouraging sit to stand***

- Make the child sit on a stool
- Hold at child's waist encouraging weight shift from hip to legs
- You can also encourage child to reach for a toy.



Figure I1



Figure I2



Figure I3



Figure I4.1



Figure I4.2

- The height should allow your child to take weight through their hands.

### ***I.3 standing against the wall:***

- Stand your child with their body flat up against knees straight. If child cannot keep knees straight, you can make them wear knee support.
- Their heels should be back against the wall, their knees straight.
- Encourage them to balance in this position.

### ***I.4 Standing against the table***

- Find a surface that your child can use to help them to remain standing up.
- Encourage them to keep their balance in this position.

## **I. Encouraging standing:**

### ***I.1. Supported standing/encouraging standing***

- Encourage them to take as much of their weight as possible and to balance themselves

### ***I.2. Encourage standing holding a bar:***

- Encourage your child to stand up against a rod or table.



Figure H1



Figure H2



Figure H3



Figure H4

## J. Walking:

### J.1 encourage walking holding hands:

- Hold the wrists and hands to support your child.
- Help your child to move their weight from one foot to the other.

### J2. Encourage walking holding walker:

- Initially you can hold on the hip and shift weight from one hip to other.
- Gradually child can try taking independent steps.

### J3. Encourage walking in parallel bars:

- Child can walk in parallel bars by holding the railing with both hands initially
- Later they can walk holding one hand

### J4. Side walking:

- Encourage side walking
- This improves weight shifts.



Figure 11

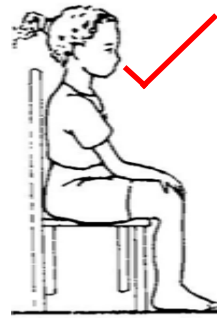


Figure 12

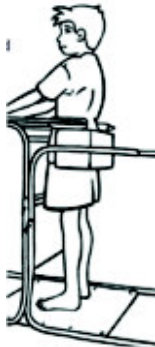


Figure 13



Figure 14.1

## K. Positioning

**K1. Sitting:** child with delayed sitting will need more support. They will require support for a longer time than other children. They may require a special chair to help them to sit in a good position, so that they can use their hands better and chew properly. After the child learns to sit, you should progress to standing.

**Correct position to sit:** Head should be slightly forward. Back should be straight and child should not lean on either side. The bottom should be against the back of chair. The knees and foot should be at the same level. Feet should be well rested or supported on the footrest. Positions to discourage while sitting: In the above two diagrams the position the hip isn't correct. You cannot initially sit strap the child at the thigh and back.

## K2. Standing:

Children with delayed standing should benefit from standing supported in a good position. Standing helps to encourage muscles that hold the body up to work. This position is the best to prevent contractures and also helps to make the leg muscles strong.

- The body should be in straight line and feet flat with equal weight on both the legs. The body hips, knees and feet should be in same alignment.
- If the child cannot stand and the body bends or he cannot keep heels on ground, you can use a forward lean stander.

*Figure L1.1**Figure L1.2**Figure L2.1**Figure L2.2**Figure L2.3**Figure L3.1**Figure L3.2*

**L. stretching:**

- It is important to have Child's cooperation for stretching.
- Position the child in such a manner so that you can avoid abnormal position or movement
- Hold the limb in stretched position and stretch very gently for a count of 20.
- Repeat the stretch and you can stretch a little more if the child is relax.
- Do stretching twice a day, once in morning and other in the evening.
- Stretch very slowly and gently, without causing any pain.
- Do not move the joints to and fro, stretch slowly, this may increase the spasticity, you have to allow the child's joints to relax.
- Avoid stretching during sudden stiffening or uncontrolled involuntary movements.
- Do not over stretch the joints,

**Below are few common stretches which you can do at home:**

***L1 Stretching of adductor scissoring:***

- Figure L1.1. shows scissoring
- Keep the child in straight lying position
- Bend both the knees
- Hold the inner part of the thigh gently, as shown in fig L1.2

***L2 Stretching of knee and foot tightness:***

- Fig L2.1 and L2.2 is showing the position of the knee and foot when the muscles become tight.
- Keep the child in straight lying position, ask someone to hold one leg, raise the other leg which is to be stretched a little high, keep one hand at the knee and with other hand gently raise the foot above, as shown in figure L2.3

**Stretching of foot muscle:**

- Keep child in straight lying position, hold the foot at the heels and gently stretch the foot upwards.

***L3. Pronator Tightness***

- Figure L3.1 describes position of the elbow, when there is tightness.
- Gently turn the elbow outwards as shown in figure L3.2

## 19. Occupational Therapy

Occupational Therapy is a treatment that focuses on helping an individual with cerebral palsy to achieve independence in all areas of their life. An Occupational therapist treats patients with Cerebral Palsy using various neurological treatment approaches aiming for complete neurological integration, bridging developmental gaps, refinement in motor performance, improving learning abilities.

### *Goals Of Occupational Therapy:*

1. To provide an individual having Cerebral palsy with positive, fun activities that will enable and enhance their physical, cognitive, gross motor and fine motor skills and help them increase their self esteem and give them a sense of accomplishment.
2. Focus on training an individual for skills that are necessary to perform the daily activities. These activities include play, self care activities like dressing grooming, bathing, feeding, fine motor activities like writing and drawing.
3. Focus on the visual motor problems, cognitive and perceptual disabilities.
4. To promote a better upper extremity use and functional independence.
5. Focuses on providing with adaptive devices and adaptive seating devices.
6. Parental counseling is again an important aspect of with regards to optimizing parental support for improving the functional abilities of a child with cerebral palsy.

Different treatment approaches are taken and considered, since no child is same, intervention for each child is specific and unique related to the strength and limitations of each child.

### *Therapeutic Intervention to improve tone of the muscle:*

- I) **Normalizing the Abnormal Tone:** In Cerebral Palsy sometimes the muscle tone is higher than normal or sometimes the muscle tone is lower than normal. Normal tone in the muscle is required to keep the body upright and to perform the movements of upper limbs and legs. Due to this varying and fluctuating tone it is difficult for the child to perform any movements of the trunk and limbs.





Figure 1



Figure 2



Figure 3



Figure 4



Figure 5



Figure 6



Figure 7



Figure 8





Figure 9



Figure 10



Figure 11



Figure 12



Figure 13



Figure 14



Figure 15



Figure 16



Figure 17



Figure 18



Figure 19



Figure 20



Figure 21



Figure 22



Figure 23



Figure 24



Figure 25



Figure 26

Hence, reduction of muscle tone is an important treatment goal, to improve comfort, care, and active function and to prevent future musculoskeletal complications. The most common kind of tone seen in cerebral palsy is spasticity.

***Facilitatory Techniques: techniques to increase the muscle tone***

- include heavy joint compression (more than body weight): to facilitate muscle co-contraction (eg: prone on elbows, quadruped, sitting on therapy ball etc).
- stretch: extending the biceps.
- tapping: tapping over the muscle belly to facilitate a particular muscle with the fingertips.
- Vibration: applied over the muscle belly to facilitate the muscle.

- Fast rocking: over a therapy ball, or in quadruped position to increase the tone.

### **Inhibitory Techniques: techniques to reduce the muscle tone.**

- neutral warmth: wrapping a child in cotton blanket/ comforter to relax and reduce the abnormal tone.
- slow/ gentle rocking: over a therapy ball in a slow speed to decrease the tone.
- slow stroking: over the paraspinal area from occiput to coccyx in prone position to reduce the tone.
- slow rolling: on mat.
- light joint compression (less than body weight): sitting or lying position, pressure over the joint

### ***Therapeutic Intervention:***

- For a Low tone Child: small and heavy joint compression, fast rocking on chair or therapy ball, fast rolling, weight bearing exercises in prone on forearm, prone on Arm, on all fours, small joint compression of hand etc.
- For a High tone Child: slow movement like slow rocking, slow rolling, slow stroking, tone inhibiting postures like neck and trunk flexion, etc.

## ***II) Integration of Primitive Reflexes and Development of normal motor patterns:***

Primitive reflexes develop during the gestation period and usually get integrated to higher levels of development by the CNS. In Cerebral Palsy due the damage to the CNS, there is incomplete integration of primitive reflexes in children with Cerebral Palsy due to which their development is halted.

Figure 1: Child showing a strong Asymmetric Tonic Neck Reflex in Supine on the bed

Figure 2: Reflex Inhibiting posture with child prone weight bearing on an extended arm on a wedge

Eg: ATNR (Figure 1)( Asymmetrical Tonic Neck Reflexes): turning of head to one side causes extension of upper and lower limb on the side the head is turned to extension and flexion of limbs of the opp side of the body. Persistence of ATNR interferes with the side turning and rolling, causing asymmetry in the body and further interfere with fine motor and gross motor function development.

Treatment includes: Positioning in a reflex inhibiting posture so that the reflex are integrated and further development occurs.

Eg: The reflex inhibiting posture for an abnormal ATNR ( Figure 2) is neck and trunk in slight flexion with hip and knee flexed and bilateral hands in close approximation to facilitate hand movements.

### ***1) Facilitating and Developing a Good Postural Control:***

A child with CP has a poor postural control because of delayed and incomplete motor development, decreased motor control, lack of stability difficulty in anti gravity movements, lack of dissociative movements(individual movement of trunk or extremities) and stereotypical movements with compensatory mechanisms. Development of postural control is also affected when there is presence of deficit is the organization of sensory inputs. An efficient postural control is important for performing voluntary skills like eating, dressing, bathing etc.

#### ***1) Facilitating and developing Antigravity movements:***

Eg: lowering a child from a sitting to supine position to facilitate neck flexion against gravity ( Figure 4). Neck and trunk extension can be promoted by placing the child in prone positions over a wedge or large therapy ball ( Figure 3)

Figure 3: Facilitation of neck extensor in prone position on a mat

Figure 4: Facilitation of neck flexors in supine position on a mat

#### ***2) Facilitation of automatic reactions like righting, equilibrium and protective reactions:***

Eg: using various surfaces like medicine ball (Figure 6), balance boards (Figure 5), bolsters etc. help challenge the body develop these reactions. These reactions are important to maintain an erect sitting and standing posture and balance while walking

Figure 5: Standing on balance board to improve the equilibrium reactions in standing

Figure 6: Sitting on a therapy ball and reaching out for objects to improve righting and equilibrium reactions.

#### ***3) Facilitation of Sensory systems:***

Eg: walking on different texture surfaces with eyes open and eyes closed. Reaching out for an object while on a swing.

#### ***4) Facilitation of Anticipatory control:***

Eg: throwing and catching a ball, kicking a ball in sitting helps in improving the reaction time.

Occupational Therapists use Neurodevelopmental Treatment Approach which is aimed at facilitating and normalizing the tone of the muscles using various facilitatory and inhibitory mechanisms, reaction and movement patterns and managing the specific reactions to the treatment of equilibrium.

Also it is said that children with cerebral palsy have a better postural control in upright position rather than the reclined or tilted position.

## ***II) Prevention Of Contracture and Deformities:***

Muscle spasticity is a significant source of functional disability in a child with CP. Due to which secondary complications like development of contractures and deformities of Upper Limb, Lower Limb and Spine, are very common in children with Cerebral Palsy.

Treat-ment Strategies aim at :

- Proper Positioning in Supine, Sidelying, Sitting and Standing
- Passive Range of Motion of all the joints of upper limbs and lower limbs
- Stretching of all the joints of upper limb and lower limb ( Figure 7, Figure 8).
- Splinting of Upper Limbs and Lower Limbs

Figure 7: Knee Contracture

Figure 8: Stretching of knee contracture in prone position.

## ***III) Sensory Integration (SI):***

SI(sensory integration) is the ability of the brain to process information to make adaptive response to the environment.

Intervention techniques should address the underlying sensory deficit and not the behavior. SI uses all senses but focuses primarily on the Vestibular(balance), Proprioceptive(joint position sense) and Tactile Senses(touch). A child's brain organizes sensory stimulation from touch and movement in order to learn and respond successfully to the environment.

- Vestibular stimulation: rocking and bouncing on therapy ball and moving in all directions, rocking on chair etc.
- Proprioceptive stimulation: includes weight bearing activities like wheel barrow walking and jumping on trampoline and hanging from a trapeze.
- Tactile stimulation: using different textures stimulation like sand playing, brushing painting activities.

## ***IV) Development of Hand Functions:***

Children with cerebral palsy display large developmental differences in hand function from that of typically developing children. Impaired hand function skills are due to problems in isolation of movements and tending to use total patterns, insufficient force application, improper timing of the movements, limitations in trunk control and inability to bring hands in midline. Hand functions include the following components like reach for a toy, various grasp patterns, voluntary release of an object, in hand manipulations and bilateral use of hand. A full evaluation of fine motor and hand skill performance is necessary:

Intervention aims at

### ***1) Proper positioning of the child:***

- Supine position for arm movements and visual regard of hands,
  - Prone position with forearm weight bearing for shoulder stability,
  - Side lying position for unilateral movements.
  - Appropriate table and chair height with optimal posture for fine motor tasks.
- 2) Improvement of Postural Tone and Postural Control:  
Eg: (refer to postural control and inhibition of abnormal tone above).
- 3) Development of Hand Skills: Promoting isolated arm and hand movements eg: proximal stabilization of trunk and shoulder is important to facilitate isolated hand movements.

**Abnormal Grasps:** There are many reasons for a grasp to be abnormal these include abnormal body posture or abnormal arm posture and synergies of movement, limited joint motion, weakness and problems with isolated finger and thumb movements, poor anticipatory grasp due to poor perceptual and cognitive abilities etc.

Treatment suggestions for improving the grasps:

- Correct Arm Patterns
- Increase the Arm and Hand range and isolated thumb and finger range.
- Improve the strength of fingers and thumb

Activities like threading large beads, smaller beads, other toys, scribbling drawing, painting, pasting, using pegboards, jigsaws with knobs, using sewing cards, posting boxes etc help improve the perception, conception and fine motor manipulation.

**Vision and Arm Pattern:** It is important to stimulate the child's visual development and to associate it with development of hand functions eg: encouraging child to look at his hands or object when reaching for it to facilitate an eye hand pattern.

Unilateral and bilateral arm patterns are included in the programme

- 1) Unilateral Patterns : reaching for an object
- 2) Bilateral patterns with both the arms in same direction: catching and throwing ball
- 3) Bilateral patterns with both the arms in opposite directions eg: pulley activities.
- 4) Bilateral patterns with each arm in different directions

Improve the hand-eye coordination through play activities like bead stringing, copying from a book or blackboard etc.

**V) Positioning and Handling Techniques:** Proper positioning and Handling techniques are to be taught and explained to the parents and caregivers while handling a child with Cerebral palsy.

**VI) Lifting a Child:** (Figure 9)

- Side turning on one side:

Figure 9: Lifting a Child

- Supporting the head and bending the hip and knees
- Holding the child close to the body
- Placing the child same way

***Carrying a Child:***

Carrying a child with CP is different for different types of Cerebral Palsy

- Carrying a Spastic Child/ Athetoid Child : Carrying with both the lower limbs separated across the trunk to prevent adduction/ scissoring of the lower limbs.( Figure 10, Figure 11, Figure 12)

Figure 10 : Carrying a Spastic child

Figure 11: Stretching a Spastic Child

Figure 12: Carrying a Spastic child

- Carrying a Floppy Child ( Figure 13): Holding the child with his back resting on the caregivers front and keeping the child hands close to each other and head supported. This position can also be used for children with opisthotonus posturing (Figure 14)

Figure 13: Carrying a Floppy Child

Figure 14: Carrying a Child with Opisthotonus posturing.

***VII) Treating Oro-Motor difficulties:***

Sensory problems in children with CP involve being sensitive to touch in and around the face and mouth (oral tactile defensiveness) due to which they find the touch of food, a nipple, a spoon, or even a hand unpleasant and may react to touch around the mouth by biting down, turning away, refusing to open their mouth, or even vomiting. Some children with cerebral palsy under react to touch around the face and mouth, due to the inadequate feeling in the mouth; it is hard for them to know how much food is in their mouth, where it is, or how to move it around their mouth and when to swallow. Children often do not know or feel when their chin is wet from drooling or that there is food in their mouth or on their chin.

Treatment: the therapist can use handling techniques to aid oral movements.

- Tapping or quick stretch, vibration to increase the tone.eg: vibrating brush.
- Deep and firm pressure and massage of the gums and peri oral areas on the cheeks, upper lip, lower lip etc, to reduce the tone.(Figure 16)
- Providing external support using hands and fingers. Eg. Using one finger to



promote chin tuck and the other under jaw for support from the side or from front to provide with head control and facilitate mouth and lip closure (Figure 15)

Figure 15 : Showing front hold position for providing with external support for head.

Figure 16: Peri Oral gentle massage techniques in sitting.

**VIII) Development of Visual Perceptual Skills:** Visual Perception is defined as the total process responsible for the reception (sensory functions) and cognition (specific mental functions).

- 1) **Visual receptive Functions:** activities like focusing, dart throwing, playing with marbles.
- 2) Visual Cognitive Functions
  - Visual Attention - alertness, selective attention, visual vigilance and divided or shared attention
  - Visual memory- short term and long term
  - Visual discrimination

Object (form) perception- form constancy, visual closure and figure Ground

Spatial perception-position in space, depth perception and topographical orientation

- Visual Imagery CP children with Visual Perceptual problems demonstrate many problems like in ADLs e.g. difficulty in combing, tying laces, matching clothes or in Play e.g. difficulty in sports, cutting, constructing, doing puzzles.

Intervention: focuses on visual perceptual training involving Developmental, Neurophysiologic, Sensory Integration and Compensatory approaches which helps in improving skills that limit function and also compensate for the limitation.

## **IX) Activities of Daily Living:**

A child with severe developmental learning delays need training for self care activities like bathing, upper body and lower body dressing, brushing teeth and feeding themselves, bowel and bladder management, functional mobility sleep and rest.

### **1) Feeding :**

Intervention in feeding involves positioning, handling and compensatory strategies. Proper positioning should be emphasized while feeding to promote oral motor functions.

Appropriate Positioning For Feeding:

- Neutral pelvic alignment of trunk. Pelvic alignment is facilitated when the child is well supported against a flat back, on a flat seat and square on the

buttocks with hip and knee in 90 degree of flexion.

- Good head neck and shoulder alignment, with neck in slight flexion or neutral position.
- Chin tuck with back of neck elongated.
- Chin tuck with back of the neck elongated.

Figure 17: Showing improper positioning for Feeding in supine on lap.

Figure 18: Showing correct positioning of child for feeding in sitting on a chair.

- Providing child with external postural support enhances stability, good alignment and easy feeding.

**Compensatory Strategies/ Adaptive Devices:** This includes use of non slip mats, suction cups, to stabilize the eating utensils.

Adapted cutlery may be more suitable, eg. Rocker knife, extended handle cutlery eg foam handle on utensils, adaptive drinking devices like cup with cut out rims, scooper bowls and plates (Figure 19)

Figure 19 : showing built up handled spoon and fork, scooped plates and bowls and cup with cut out rims.

- Adapted chairs, trays attached to table etc.
- Adapted chairs, trays attached to table etc.

### ***Practical tips***

- Normalizing the child's tone as much as possible before beginning the feeding process.
- Observe the child while he/she is eating.
- Make sure the child can see plate, the food which is on it and the spoon bringing the food from the plate to her mouth.
- Talk to her/him about the process and let her/him see, feel and smell the food, feel the plate and the spoon.
- The feeding person should be seated directly in front in order to maintain proper position.
- Table should be positioned at axilla height and close to the chest so distance from plate to mouth is reduced.
- Chewing may need to be encouraged slowly and patiently by very gradually increasing the density of texture and later on the lumpiness of the food offered.
- Encourage the child to pick up food (such as cakes, biscuits, bread or fruit) in her hands and bring it to her mouth.
- Use different food temperatures and textures to increase the child's awareness of what is in his mouth.

- Firm pressure is more acceptable to the child than light touch.
  - Placing the mirror in front of the child during meal times helps his feeding skills.
  - Give the child the drink that he likes best allowing him to make a choice when you teach him to drink.
  - Therapist can guide the extremity in the correct pattern if required.
- 2) **Dressing:** Learning and participation in dressing is a major step in achieving independence. Even with limited motor and sensory skills dressing can be made easy by motivating the child to actively participate and reducing demands placed on the child.

### **Adaptations:**

#### *Adaptive clothing*

- Loose clothing that is free from unnecessary fastenings which should be limited to few layers.
- Use of Velcro and elastic band clothing instead of buttons or zippers.
- Front openings, pullovers, large buttons, stretchy clothing.

#### *Practical Tips:*

- Work on undressing first, as it is an easier skill than dressing.
- Always put the clothes on the most affected part of the body first and undress that side last.
- Positioning child on the floor is safer than on a chair.

Figure 20: Showing UB donning of tshirt in Sitting Position to inhibit extensor posturing

Figure 21: Showing LB donning of pants in Sitting Position to inhibit extensor posturing

- Techniques that inhibit spastic postures will facilitate the movements in and out of clothing. If her legs are bent before putting on socks and shoes it may help ease stiffness in her ankles and feet and her toes are less likely to curl under (Figure 20, Figure 21).
- Encourage to stand and hold on to furniture.

### **3) Bathing**

Achieving cleanliness is essential for maintaining a good hygiene. Bathing can be made fun and a special bonding time with the mother/ caregiver. Occupational therapist can use bathing therapeutically to enhance motor and sensory skills.

## **Adaptive Devices**

### ***Hand Held faucet***

- Soap on string, soap tied in a loofah or liquid soap
- Use of railing, grab bars in the bathroom
- Use of adaptive bath chairs
- Semi inflated inner tube can be used as a positioning device
- Nonskid mats
- Hydraulic grab bars

### ***Practical tips***

- Proper positioning to normalize the tone and providing a sense of security, rather than challenging his sense of balance.

Figure 22: Bathing the child in Prone position

- Bath sponge wedge can be used to bath an infant in both sitting and lying prone positions (Figure 22).
- Bathing can be time which can be used to teach various concepts for example arm in, arm out, tub full, empty, wet, warm, cold and working on teaching various body parts and body parts identification. Thus bathing provides the child with many opportunities to learn cause and effect relationships, spatial relationships and tolerance of different sensations.
- The time following a bath can also be very productive. Eg: a fast run with a terry towel can help the child learn to process sensations and can lead to better body awareness.

### **4) *Toileting:***

Independent toileting is very important for achieving self maintenance. Toilet training can be quite challenging in a CP child as the child must be temperamentally and physically ready to accept toilet training as well as able to understand the process in order to have any success.

### ***Adaptive Devices:***

- Hand held jet sprays
- Use of toilet papers, use of wet tissues
- Soap on string or soap tied in a loofah or liquid soap
- Use of railings and grab bars.
- Adaptive commodes or toilet chairs

Figure 23 : Lost Cost Modified toileting commode for a child with cerebral palsy

- Footstools or foot rest to support the feet
- Use of protective straps to maintain safe and proper posture
- Use of Non skid mats to prevent slipping.

***Practical Tips:***

- A fairly casual, non confrontational introduction to the process will help reduce any stress related toilet training.
- Visual breakdown of task on wall
- Habit training to go at the same time to toilet
- Reinforce them for their success or for sitting patiently on the toilet and trying.
- Instruct caregivers to follow the same routines when at school.

**X) Hand Writing Skills:**

Writing is a fine motor task required to compose stories, complete written examinations, copy numbers etc. It is complex task which requires synthesis and integration of memory retrieval, organization, problem solving skills, and language and reading ability, ideation and graphomotor function.

The building blocks of early handwriting are

- Spatial and body awareness
- Postural control
- Visual Perception
- Fine motor control
- Directionality
- Hand writing

Interventions focuses on

- Neuro Developmental Approach: postural and limb preparation activities like jumping on trampoline, pushups, bear walking etc to modulate the tone.
- Biomechanical Approach: Sitting posture should be with feet firmly on the ground, height of the table should be 2 inches from the flexed elbow, paper position should be slanted so that it is parallel to the forearm of the writing hand, pencil grasp should be ideally dynamic tripod grasp, pencil with a wide diameter, various writing paper, ( lined, unlined, double lined, textured, margins)
- Sensorimotor Approach: involves controlling sensory input through selected activities to enhance sensory systems. An inclined, vertical, horizontal, writing

surface, writing tools like crayons, sketch pens, vibratory pens and using different textures like sand, shaving cream, talcum powder.

### ***Adaptive Writing Equipment:***

Pencil grippers and weighted pencils and handi-writers (soft elastic looped around the writing utensil and wrist that keeps the utensil in appropriate space of the hand) ( Figure 24, 25)

Figure 24, 25: Various Writing Devices.

Adaptive writing paper that is color coded, sticky or rough on one side or has larger lined area.

## **XI) Mobility( also refer to physiotherapy chapter )**

- Wheel chairs such as go-karts, powered chariots, tricycle with adaptations ( hand-held or special type).
- Powered wheelchair with joystick, head switch, or siff/puff controls for severely impaired children.
- Corner seats: To improve the sitting posture and keep the lower limbs abducted and proper weight bearing on the bottom (Figure 26). Figure 26: Child sitting in a Corner Chair
- Grab bars and railings.

## **XII) Play Skills and Leisure Activities:**

Play can be an important part of the learning experience and development of motor skills for a child with Cerebral Palsy. Selecting an activity should incorporate the child's interests and the skill he possess to participate in safe playing.

- Appropriate adapted equipment, such as wedges, bolsters, bean bags, CP chairs, maybe used.
- Make certain your child changes positions frequently. Children should be encouraged to play on different surfaces and at safe heights.
- Position child with both arms forward when playing with toys.
- Make certain that the child can see what is happening.
- Talk to the child at the child's eye level.
- Give the child ample time to respond.
- Maintain a good balance between noisy, active play and quieter, less strenuous activities.
- Present toys that encourage your child to reach and grasp with the hand that is more difficult to use, but allow the child to use whichever hand he chooses.

- When teaching dressing to the child, put the more affected arm or leg into the clothing first.
- When interacting with your child, take the more affected hand.
- Encourage bilateral activities such as rolling clay, or throwing a large ball.
- Provide multi sensory input toys that have interesting things to see, hear and feel.
- Avoid too noisy small play items.
- Grade the level of activities, and gradually increase the complexity of the activity.
- A mirror can be a great aid in playing so that the child can get visual feedback.
- Toys that have large handles or knobs to grasp should be used.

*Age Appropriate toys used to enhance play behaviours.*

**0-2 years**

- Play mat and frame with dangling toys
- Rocking and bouncing games.
- Making lots of babbling and cooing noises.
- Tickling games
- Building blocks
- Story books- with auditory games
- Peek-a-boo games
- Banging on musical drums
- Imitation and turn taking
- Playing with mirrors, press toys.
- Unwrapping the toys

**1-3 years**

- Finger puppets
- Tunnel games
- Surprise bags full of toys and interesting objects for your child to find
- Pulling and pushing activity
- Object identification
- Pretend games with dollies and teddies
- Finger painting and brush painting

- Paper crumpling and paper tearing

**2-4 years**

- Story books
- Clay modeling
- Ball games
- Obstacle course
- Sticking
- Stamping activities
- Spotting the difference
- Shape and color matching
- Imitation games
- Imaginative play, eg turning boxes into toys (such as castles, cars or space ships)
- Action rhymes
- Listening games
- Music making with homemade instruments.

**XIII) OT Intervention in School for CP Children:**

OT in school focuses on the child's ability to participate in functional school activities. A problem solving approach is used to identify the difficulties the child faces and to identify the intervention strategies. Mental retardation and Learning Disabilities are some of the problems which the CP child may have to face.

Parents may require counseling regarding the type of School which will best suit the child. The Occupational therapist is one of the members of a child's IEP (Individualized Education Program) team.

***Strategies used in School:***

- Reframe the teacher's perspective eg: by explaining the issues and the underlying deficit the child seems to be facing.
- Improve the child's skills eg: use of practice worksheets
- Adapt the task eg: use of keyboards to take down notes
- Adapt the environment eg: keeping visual distractions to a minimum.
- Adapt the routine eg: extra time to complete worksheets.



## 20. Aquatic therapy

Aquatic therapy is defined as *“The use of water and specifically designed activity by qualified personnel to aid in the restoration, extension, maintenance and quality of function for persons with acute, transient, or chronic disabilities, syndromes or diseases”* by The Aquatic Therapy and Rehabilitation Institute. In simple terms aquatic therapy means making use of different properties of water to facilitate functional recovery and independence of children with CP.

### Properties of water

#### 1. Buoyancy

Buoyancy is the upward push that water exerts on the immersed body. It is responsible for the weightlessness experienced in water. Therapeutically this can be used to relieve the compressive forces on the joints. Deeper the immersion greater is the weightlessness. If the child is immersed till umbilical level then the effective weight on the legs is reduced by 50%.

Weightlessness is a very important phenomenon for therapeutic benefit. Weight bearing joints like ankle, knee and hip joints can be offloaded in water which helps reducing the stiffness of the muscles.

#### 2. Hydrostatic Pressure

Is the pressure exerted by water and depends upon the density as well as the depth of immersion. The deeper we immerse the child the greater is the force. This is particularly helpful for reducing the swelling and providing passive relaxation through deep pressure. Hydrostatic pressure is also important to push the blood from the legs and thighs up increasing the blood returning to the heart. This also helps in increasing blood supply to the brain and therefore cognitive functions. The increased blood supply to heart is important for good cardiovascular health.

#### 3. Density

Water is thicker or denser than the air. The density of water is more than the air and almost similar to human body. The density of water is important therapeutically as it is this quality of water that supports the child once immersed in water and also

exerts an upward force. Because of the difference in the densities of various tissues in the body, a leaner child with lesser fat tissue will tend to sink more in the water whereas children with more fat tissue will tend to float.

#### **4. Viscosity**

Viscosity of water is the amount of friction generated with a movement in water. The friction is significantly higher in water than air which provides resistance to any movement of the body. This makes water an excellent strengthening tool. The resistance provided by the water is dependent upon the speed of the movement and direction of the movements which are patient dependent. In painful conditions if the patients stops the movement the resistance drops to zero and therefore the strengthening activities can be performed within the limits of patient's tolerance.

These unique properties of water provide desirable environment for the children with cerebral palsy. Immersion in water brings about beneficial effects in various body systems of a child with cerebral palsy.

### **Beneficial effects of water immersion**

#### **Heart and lungs**

Water exerts compressive pressure on the blood vessels and pumps up the blood from limbs to the heart. In children with cerebral palsy because of inactivity or muscle weakness or low muscles tone the blood circulation may be sluggish. This causes the blood to be pooled in the lower extremities and toxic waste to be accumulated. Immersion in water helps clear the toxic wastes. Improved blood pumping in the heart also provides heart with more blood to pump out improving the blood supply to the lungs and better oxygenation of the blood.

Compressive forces of the water provide resistance to the respiratory muscles (muscles required for breathing) and help strengthening these muscles. Exhalation or breathing out is passive rebound compression of the rib cage, as the tone of the muscles alters this relaxation is difficult. Incomplete relaxation leads to exhalation of the air from only the upper parts of the lungs and accumulation of air in lower parts. Such accumulation could have various detrimental effects on the body. Immersion in water compresses the rib cage helping in better exhalation and lesser accumulation.

#### **Muscles and bone**

Immersion in the water increases the blood returning to the heart and in turn the blood delivered to all the organs. Most of this blood is supplied to skin and muscle tissue. Blood supply to the deep muscles increases nearly threefold during chest level immersion. Immersion offloads the joints facilitating relaxation of the muscles and smooth movements. The resistance provided by viscosity of water for any kind of the movement helps in stabilizing the tone of the muscles. Joint compression combined with increased blood supply help in reducing the tone of the muscles.

Viscosity of water helps in strengthening the muscles. Improved circulation helps improve flexibility and pliability of the muscles.

### **Brain and Nervous system**

Increased blood supply to the brain leads to improvement in memory and other cognitive symptoms. The child is more attentive in the water. Water immersion facilitates stimulation of para-sympathetic nervous system which facilitates relaxation of the body and suppression of the sympathetic nervous system that is responsible for the responses of anxiety. Immersion in water therefore facilitates relaxation and further suppression of the nerve signals that are responsible for increased tone of the muscles.

These beneficial effects of water immersion are used by for therapeutic benefit by aquatic professionals. It is important to understand that although immersion in water is beneficial, goal oriented and targeted exercises are required for optimum recovery in cerebral palsy.

### **Benefits of aquatic therapy in cerebral palsy**

- Sustained reduction in spasticity
- Improved muscle and movement co-ordination
- Improved oromotor control
- Improved respiratory capacity
- Better flexibility of the muscles
- Improved walking patterns
- Improved eye – hand co-ordination
- Improved muscle strength
- Improved cardiovascular endurance
- Regularization of the sleep patterns
- Reduction in the abnormal involuntary movements
- Reduction in the sudden spasms of the muscles

### **What to expect in an aquatic therapy session?**

Aquatic therapy does not mean swimming. Aquatic therapy includes purposeful therapeutic movements or exercises performed in order to achieve reduction in the symptoms of CP. There are various techniques in aquatic therapy. An exercises session will consist of a combination of these techniques and approaches like Halliwick technique, Bad-Ragaz Technique, Clinical Aai-Chi, Aquatic exercises, Aqua aerobics and Passive relaxation or Watsu. Mostly in cerebral palsy an exercise session will be conducted one – on – one by the therapist. Occasionally therapists may form groups of children with similar impairments and limitations and conduct group session with parents.

In the beginning the exercise session will emphasize on adaptation to water environment and being comfortable in water. Therapist may choose to engage the patient in various play activities on the surface of the water. This will be followed by respiratory and oromotor control in water where the child will slowly be introduced to under water environment facilitating better breath control. Various play activities like pushing the balloons, balls or other small objects by blowing on them, making a well in the water, blowing bubbles in the water, flipping discs in the water by blowing on them may be used to improve oromotor especially the breath control.

Once the child is comfortable in water and has achieved good breathing control, various rigorous goal oriented activities will be performed during subsequent exercise sessions.

### **What precautions to take during and after an exercises session**

- Consume plenty of water during the exercise session
- Make sure to empty the bladder and bowel of the child before immersion to prevent accidents in water and soiling
- If the child needs to sit on the edge, to enter and exit the pool then carry a mat on which child can sit to avoid abrasions and wounds.
- Make sure that there is no open wound on the body

### **Is aquatic therapy an alternative to land based therapy?**

No aquatic therapy is not an alternative but a adjunct to it. Land based rehabilitation and aquatic rehabilitation needs to be performed together. Neither is alternative to the other. Although there are some advantages of aquatic rehabilitation as compared to the land based rehabilitation both are essential for optimum recovery.

### **Benefits of aquatic therapy over land based therapy**

- There is less weight on the joints, the child is well supported and joints are not under stress like on land. Therefore aquatic therapy helps achieve the benefits of land based therapy without causing any harm to the joints.
- As the children are able to perform the tasks in water much easier than on land, their confidence and activity participation increases.
- Activities in water are more fun and interesting for the children therefore there is better engagement of the children in a session and better adherence to therapy than on land.
- For children with severe motor deficits and significant movement restriction on land. Aquatic environment provides some freedom for movement.
- The risk of fall significantly reduces in aquatic environment

Therefore aquatic therapy may be preferred in some children or preferred over a certain phases in a child's development. It provides an excellent medium to train the child and improve their motor impairments. It is fun and enjoyable ensuring long term adherence. In adults it helps to maintain various cardio-respiratory health parameters. It is relatively a new form of therapy in India, however it has been an established form of therapy worldwide for decades. It is safe and very effective in improving the quality of life of the children with cerebral palsy. However aquatic therapy alone is not sufficient and must incorporated in the multidisciplinary rehabilitation program.

## 21. Speech therapy

*Contributed by : Ms. Gayatri Hattiangadi & Mrs. Maya Sanghi*

Having a child with severe developmental disabilities which are long-standing can be a severe challenge to parents whose entire lives are transformed into being caregivers, proxy clinicians and watchful nurses tending to their children. Their lives are half lived in hospitals, nursing homes and doctors' clinics for the many medical ailments suffered by their children and in the therapy clinics of rehabilitation professionals which they need to visit regularly for consultations and therapy. The tremendous strain -physical, mental, emotional, financial - on them is consistent and unrelenting!

In spite of all this, their courage, commitment and endless striving for the betterment of their children is exemplary and commendable! Parents are all the while searching for any course, any new treatment modality being researched, any bit of new information that comes their way which might help their child with Cerebral Palsy and they try their level best to make it available for their child. In a country like India where, the available resources for children with disabilities are very few and more likely to be in metropolitan cities and larger towns, it is the need of the hour to have ready and easily applicable clinical literature at hand, so that the caregivers of these children may work towards enabling their children towards better health and functioning. This may help them to reduce the participation barriers of their children and enhance their functioning in their respective environments.

Parental/ caregivers' role in the management is paramount and the most important determiner of the success of the program as it is only with their support and carry-over of the goals and activities into extra-clinical settings, that any therapy will prove to be effective. They need to be active participants in the therapy program, should be given extensive demonstration sessions and detailed home programs. This chapter is meant to be a 'ready reckoner' for caregivers of children with Cerebral Palsy to help them deal with the manifold problems dealing with hearing, feeding and communication. The brief overview of the problems faced by these children has been presented earlier and in this chapter easy -to -apply strategies, clinical tips and recommendations are presented.

The Audiologist and Speech Language Pathologist (ASLP) is responsible for the effective assessment, diagnosis and management of the disorders related to swallowing

and feeding, hearing and communication, affecting children with CP. Management by an SLP will vary according to the age of onset of the pathology and age at which the child reports to the SLP, affected domains, severity, pathophysiology, and associated problems. An important guideline is that for the assessment of deficits, the child's chronological age needs to be considered and for treatment planning, his developmental age. It then becomes clear to the caregiver as to at what level the child is, at present and what is the lag between present and the level he needs to achieve within the constraints of his impairment. In all these endeavors, it is important that neither the caregivers nor the professionals lose the sight of the child as a whole. When all the team members and the parents work in coordination, it will result in faster and better progress in all the affected domains of the child's development. The purpose of this endeavor is not to replace sessions with the rehabilitation professionals, but provide a support to caregivers of children with CP, where such help is not available, or until such sessions can be arranged. It is hoped that this venture is found useful and practical for them. The following section deals with the management of primary disorders- breathing disorders (from the SLP's perspective); swallowing/feeding disorders; hearing disorders- and secondary disorders overlaid on the primary ones- communication and speech.

## **MANAGEMENT OF BREATHING DISORDERS FOR IMPROVING VEGETATIVE BREATHING**

### **Relaxation and Breathing Exercises**

These are meant to relax the muscle tone and reduce rigidity of the respiratory musculature and are to be primarily done by the Physiotherapist. It is essential that these need to be also done by the SLP in consultation with the PTist owing to its relevance in swallowing and speech production. The exercises need to be demonstrated in a clinical set up and then to be implemented in the daily regimen by caregivers. Since PTists trained in Neurodevelopment Treatment (NDT) principles and treatment can help a great deal in this regard, this exercise regimen has to be planned in coordination with the physiotherapist trained in NDT. NDT is the best treatment approach for enhancing neuromuscular control and breathing capacity which is imperative for the child's general health and also for his later speech development.

Some exercises that may be of help.

1. **For enhancing Inhalation and Exhalation:-** The caregiver makes the child lie on his back (supine position) and just places his/her palm for a few moments on the child's abdomen without any overt pressure. This seemingly simplistic positioning actually facilitates the breathing and steadily you see the abdomen rise due to the inspiration occurring. The caregiver can then flex the child's legs at the knees and then press his bent legs towards his abdomen, thus aiding in expiration. This sequence could be repeated 5-6 times.
2. **For reducing rigidity and hypertonicity of ribcage and respiratory muscles:-**

The child is made to lie on his stomach (prone position) and taking the child's spine from the nape of the neck as the reference position, the caregiver supports the child's trunk with one hand and with the side of palm placed on the outer side of shoulder of opposite side, exerts deep pressure and moves in a transverse position towards the spine. Then the same is done on the other side and ending the transverse movement a few cm below on the spine in an almost V shape. This sequence is repeated until the lower end of the ribcage. Then again start the whole exercise. This is done 5-10 times each time.

Pics showing exercise to reduce hypertonicity of ribcage

3. **For relaxing the ribcage:-** The child is placed in the prone position and the caregiver with the right hand held taut with fingers together and thumb at right angles, places the hand on the child's left side just below the armpit, with the thumb below and fingers above and held taut thus, with the contact region on the child's body being the space between the thumb and fingers, the caregiver exerts deep pressure and as swiftly as possible moves it downwards in a vibratory mode till the base of the ribcage, then again similarly 5 times and then for another 5 times on the right side.

These exercises should be done 5-6 times each time and about 4 times each day along with the others for speech facilitation. These are very helpful to relax the respiratory musculature and ribcage which improves the respiration and thus has a positive impact on speech as well.

## MANAGEMENT OF HEARING IMPAIRMENT (HI)

It is a challenge to work with a child with multiple impairments- CP and HI- and treatment of HI needs to be planned in consultation with the ENT surgeon and the ASLP. Referral to the ENT surgeon is imperative for treatment of conditions that can be medically or surgically treated. Once the best of those options have been tried and the child has irreversible sensorineural hearing loss, then the Audiologist assesses the nature and degree of HI through a battery of audiological tests, such as:-

- **Behavioral Observation Audiometry (BOA)** which gives an idea of the functioning of the better ear with the help of sounds presented from sound makers, ranging across different frequencies and intensities, and speech sounds presented at varying distances from child. Physiological responses such as eye blink, changes in breathing, startle responses are considered as responses to sound stimuli when these occur immediately after sound presentation. BOA is particularly helpful in these children.
- **Visual Response Audiometry (VRA)** wherein the child is conditioned to look at a visual stimulus on the presentation of the sound stimulus in a free field setting.

This may be difficult in a child with CP who may not be able to localize his head towards sound source due to poor neck control, but if eye tracking is present,



that could be considered to judge a child's response.

- **Pure Tone Audiometry (PTA)** which measures the behavioral thresholds of hearing sensitivity in the two ears and the type of hearing loss and is a standard test of choice
- Electrophysiological testing such as **Brainstem Evoked Response Audiometry (BERA)**, which is an objective test to obtain the hearing thresholds to click and tone burst stimuli, and is considered a test of choice in children with CP as the child's active participation is not required. BERA can be done in natural sleep or under sedation .
- **Impedance Audiometry** or Immittance Audiometry is used which tests middle ear functioning and stapelial reflex which can help in diagnosing middle ear conditions such as middle ear fluid, ossicular chain fixation/discontinuity etc. It also helps to estimate degree of hearing loss based on stapelial reflex threshold and helps in differential diagnosis between cochlear and retrocochlear site of lesion.
- Other tests such as **Speech Audiometry, Otoacoustic Emissions (OAE)**, also may be used.

Based on the type and degree of the hearing loss, the child may be fitted with suitable amplification (Hearing Aid fitting) in case of sensorineural and mixed type of hearing impairments. In a child who has HI, fitting with suitable hearing aids can be time consuming and challenging. This just gets all the more challenging when there are multiple impairments that is, CP and HI and even more so if such a child is also having cognitive impairment as may be seen in children with post- Rubella syndrome. It is crucial that the child is fitted with a hearing aid most suited to his HI for best acceptance. If the hearing status is not a true estimate, there is a risk that the child may be fitted with a hearing aid too powerful which the child would understandably reject, and if it is less powerful it not meet his needs. Hence it is after many sessions and painstaking efforts of an Audiologist that hearing aid fitting may be successfully completed. It is necessary that Hearing Aid trials are done with the child's customized earmoulds. Behind-the-ear (BTE) type hearing aids may be mostly considered as best suited for these children.

In recent times, there is the additional option of cochlear implant (CI) surgery. It is a very important role of an audiologist to do a pre-CI evaluation and determine candidacy for CI surgery. Only when the hearing loss indicates a cochlear loss of a permanent nature and there is not a sufficient degree of improvement with amplification tried with at least 6 months of Hearing Aid fitting, is this surgery considered. After fitting with suitable hearing aids or with CI, the Audiologist & SLP begins with rehabilitation and initiates intensive speech and language therapy.

Audiological testing and rehabilitation is a very specialized domain and is beyond the scope of this chapter to give more information here. Caregivers are advised to consult an Audiologist for details related to the above mentioned domains.

## MANAGEMENT OF FEEDING AND SWALLOWING DISORDERS

**Oral motor evaluation** of the pre speaking child can be best achieved through modified feeding. Love, Hagerman and Tiami (1980) have presented an experimental clinical dysphagia scale wherein 5 feeding tasks are used for assessment:

- Biting
- Sucking
- Swallowing
- Chewing soft food
- Chewing hard food

The children are observed while having assorted foods such as spoon foods, chewables and drinks. Their positioning and any use of adaptive equipment are also observed. Based on the deficits seen, the SLP as the swallowing therapist can plan the therapy.

Swallowing therapy is indicated when the actual stages of swallowing, the triggering of swallow reflex and the oral and pharyngeal transit time is worked upon, whilst at all times focusing upon airway safety and ensuring safe swallowing. Hence, this requires the active involvement of the SLP in the capacity of a swallowing therapist. The first priority is to focus on ensuring airway safety. Once safe swallow is ensured, the nutritional and hydrational requirements are considered for which, intensive swallowing therapy is necessitated.

## THERAPY TO IMPROVE FEEDING

Attempts to improve feeding will include the caregiver helping the child with CP with positioning of food in the mouth, manipulating food in the mouth with tongue, chewing bolus of varying consistencies, re-collecting bolus into a cohesive mass prior to initiation of oral stage of swallow and organizing lingual action to propel the bolus posteriorly. (Arvedson,2002)

Pic of child placing bolus posteriorly to facilitate chewing

See picture 4 shows some adaptive feeding equipment and 5 shows a child with oral stage dysphagia being fed using a head back posture to position soft food.

The approach using 5 T.'s as suggested by Arvedson (2002) is especially relevant in this context:-

- **Taste:-** A variety of foods ranging in sweet, salty, sour and a little spicy has to be introduced one by one over time
- **Textures** of foodstuffs of varying consistencies need to be graded from soft solid to semisolid, to thick liquid to thin liquid in order of increasing difficulty for child
- **Temperature :-** Cold temperature is known to reduce spasticity and help in mobility of tongue for swallowing. More details given where PNF is explained.

- **Total intake:-** The child with CP, by and large is a poor eater and the total volume of food per meal has to increase gradually. For example, a child has half a katori of khichdi which needs to increase over time as suited to his nutritional requirements.
- **Time :-** The time taken to swallow a bolus as well as the time taken for having the whole meal is measured and noted per meal, in a small notebook or diary and attempt is made to reduce these times with the swallowing therapy. Reduction of time can be used to measure swallow therapy outcomes.
- **All the above points** need to be carefully monitored by maintaining a **diet chart** tabulating the quantity and nature of intake, and response of the child during feeding.
- Inclusion of a **Dietician** and an **Occupational Therapist** in the team along with the SLP /Swallowing therapist is very important.

Presented below are some specific techniques that may be used for improving swallowing / feeding in children with CP and which help to lay the ground for speech production.

**Exercises to prepare the oropharyngeal musculature for swallowing & speech production :-** (Compiled by Sanghi,(2007), drawn from basic inputs Crickmay, ....and adapted with some additions based from clinical experience, used for clinical teaching but hitherto, unpublished)

**A) *For normalization of muscle tone-***

- Put the child in an appropriate posture in consultation with the Physiotherapist. These postures or positions are conducive to speech and likely to help the child with CP to be most relaxed

**B) *To facilitate independent movements of head, shoulders & neck-***

- Put child on a cot on his back, arms down by side hips flexed, put your arms under his spine and encourage him to let his head fall back over your arms in loose and relaxed way. Flex the shoulder forward and let neck extend.
- Place the child in a supine position (lying on back) with legs hanging over end of bed, and extend his shoulder backward and head flexed forward.
- Place the child in a supine position, passively move first shoulder, then other independent of each other. With child in same position, tilt/move the child's head first to one side and then to other.
- Hold child's shoulders back and encourage making small independent movements of head.

**C) *To desensitize oral musculature***

- Hold child firmly in a comfortable posture and gently touch and move

hypersensitive parts starting from periphery , that is upper part of face, then cheeks gradually moving towards mouth.

- i) PIC Light pressure on sub-mandibular region and thyroid region to facilitate swallowing

As a rule of thumb, if a reflex is absent for the particular age, **stimulate**. If reflex is persisting beyond a certain age, **inhibit**.

**D) To stimulate age appropriate feeding reflexes in infants and older children.**

- i) To stimulate **Rooting reflex**

- Stroking outwards firmly from the corner of the mouth along the cheek

- ii) To stimulate tongue groove and **suckling** in an infant

- Stroking the lower lip and tongue tip in and out of the mouth
- Firm tapping of the corners of the mouth

- iii) To stimulate *sucking reflex*

- A medicine dropper can be filled with the drink the child likes. One or two drops can be put into the oral cavity and the lips and tongue can be stroked. If done frequently, the child may develop a weak-sucking behavior

**Later straw can be used.**

- iv) To stimulate *biting reflex*

- Touching the teeth of the child and with the other hand encouraging rhythmic up and down movements of the jaw

- v) To stimulate *chewing reflex*

- Facilitate tongue movement manually without and then with resistance
- Placing food, such as a wedge of Parle G biscuit between the side teeth or gum ridges. Consistency safe for child to be chosen.
- Massaging the cheek from outside when food has been placed in the cheek pouch
- Important to introduce solid foods in his daily diet to give him more and more of chewing of harder solids in a graded manner, initially starting with soft foods like boiled potato, boiled egg, banana, then moving towards peeled apple, partially cooked carrot sticks.

**Note:** When swallowing reflex is sluggish, dis-coordinated or absent, it is imperative to consult an SLP/swallowing therapist to guide the caregiver about a safe swallow. Choking on food may be a complication if oral feeds are tried by caregivers prior to ensuring safe swallow, hence extreme precautions are to be taken

**E) To inhibit primitive reflexes in infants and older children.**

- i) To inhibit *tongue thrust*

- Placing a spoon/finger on the middle of the tongue and making downward vibratory movements a number of times
- Activities for jaw stability given in the earlier section
- ii) To *desensitize hyperactive gag*
  - Achieving chin-tuck posture quickly and leaning him forward. Maintaining the posture till the child deals with the bolus placed in mouth that caused the gag
- iii) To *inhibit suckling reflex*
  - Touching his lips with finger or straw and with other hand prevent them from moving into sucking position particularly when child is thirsty
- iv) To *inhibit biting reflex*
  - Gently but firmly holding the child's mouth closed while at the same time stimulating reflex either by bringing his/her fingers close to his mouth or by touching his teeth
- v) To *inhibit jaw clenching*
  - Encouraging child to put his fingers in his mouth which encourages licking, sucking and relaxes mouth and jaw
- F) Teaching normal mouth positions
  - Help child to align his teeth and close his mouth when jaw position is normal
  - Place one hand gently under chin and hold in this position
  - With other hand stroke cheeks and lips for relaxed expression of face
  - Gradually release pressure under chin by removing hand
  - Child takes control over himself for few seconds/minutes
  - New sensation of closed mouth- done repeatedly brings about longer periods of control
- G) *To improve lip seal and reduce drooling*
  - Facilitation of lip closure by bringing the upper lip and lower lip together by holding them between your two fingers. To be done for a few seconds but to be done as frequently as possible.
  - Iced candies can be used. It relaxes spastic muscle and activates flaccid muscle. It improves lip closure and tongue movements. Encouraging use of mirror for imitation. When chilled foods are to be avoided, lollipops can be used.
- H) *To achieve jaw and lip closure. These also help in preventing tongue thrust and facilitate swallowing.*
  - Clinician / caregiver sits facing the child and holding the child's jaw below the lower lip with the thumb and supporting the lower part of the jaw with the index finger on the cheek and remaining fingers below the jaw.

- Clinician / caregiver stands behind the child and holding the jaw with the index finger placed below the lower lip and thumb on the TM joint.

## **I) To enhance oral sensory awareness**

To desensitize hypersensitivity of face and mouth – Increase stroking gently, starting at the face. With a cotton face -towel covering your fingers, stroke gently from the base of child's earline towards lips, below right ear towards right side of lips, and below left ear towards left side of lips together in a clean sweeping movement. Do it around 5 times. This helps to relax the child's facial muscles and may reduce spasticity.

Proprioceptive neuromuscular Facilitation :Stimulation in form of Icing and Brushing is done to increase oral sensory awareness and stimulate movement.

Icing can be done five seconds each, using ice cubes kept in sterile surgical glove or using iced cotton wool buds. Effects of icing are immediate. Two methods of icing may be done Slow icing –to reduce spasticity.Fast icing –to stimulate muscle tone

Brushing –using “Florite”brush ( infant gum and tongue cleaner) dipped in honey and lime solution to add taste and to serve as a lubricant to stroke along the appropriate muscle such as tongue, prior to the required activity. Useful to stimulate flaccid muscles. Time lag of 20-30 minutes is expected between brushing and getting optimal results

Tapping – Light but firm tapping needs to be done on the cheeks from the earline to the lips, from either side. Then this process is to be done around the lips in a circular fashion and then inside the mouth, on the anterior surface of the tongue. At each level, it should be done for 2-3 minutes each.

Initially, a demonstration needs to be given by an SLP and under her/his guidance, the caregiver needs to be trained who then needs to follow a regular regimen of doing this 10 mins each time spread over 5-6 times each day. Intraoral PNF should be avoided after meals as they may trigger nausea and vomiting. Some of these sessions of PNF may be done prior to mealtimes as this stimulation may facilitate swallowing/feeding initially and later result in better speech development too.

## **J) To strengthen oral musculature**

- i) This can be demonstrated by asking children to imitate caregiver and do lateral movements and protrusion and retraction, elevation and depression of the tongue when feasible and then against resistance.
- ii) When tongue is too rigid, or too weak, the caregiver can gently hold it with sterile gauze piece and move in the required directions.
- iii) A piece of chocolate or jaggery can be stuck on the upper lip or alveolar ridge (region behind the upper teeth). The child will elevate tongue in his attempts to lick it.
- iv) Similar with lateral stretching of lips, pursing them and rounding them and

later the same to be done against resistance.

- v) Jaw movements up/down and lateral movements to be done and then against resistance from caregiver. Exercises for jaw mobility have been explained in H) above.
- vi) Blowing exercises by puffing cheeks and holding pressure on a count of 1-3 or 1-5, or by blowing candle or blowing off pieces of paper, can be demonstrated which help in improving lip seal, increase intraoral pressure and reduce drooling. This further improves swallowing and later help in building intraoral pressure as required for speech.

### **K) Some general guidelines during feeding and drinking**

- i) Approximately 15-20 minutes before meal time, use pressure stimulation of the face, around the lips, stretching the top and bottom lip from mid-line outwards and stroking downwards on the top lip and upwards on the bottom lip with fingers or fluorite brush.
- ii) Present small mouthfuls, slowly and rhythmically.
- iii) Feeding with the spoon should be done horizontally without angling the spoon upwards. Assist him in drawing the food from the bowl of the spoon by manually facilitating jaw and lip closure as discussed earlier. Alternatively, transferring the spoon horizontally between the side teeth and scraping there.
- iv) Do not tip the child's head back when giving drinks. Use a cup with a cut out section to prevent the need to do so.
- v) Adaptive feeding equipment may be used at home to assist in feeding.  
PIC-5 Adaptive feeding equipment
- vii) Initially feed to the preferred side in the child's mouth or the side where he shows most reaction to food.

## **MANAGEMENT OF COMMUNICATION DISORDERS IN A NON-VERBAL/ MINIMALLY VERBAL CHILD**

In assessing communication, it is imperative for the ASLP to do detailed audiological evaluations to rule out hearing impairment and if confirmed, to do the necessary intervention. More about this is given in the section on management of hearing disorders.

With the help of a psychologist, the child's cognitive status needs to be understood and performance IQ or SQ needs to be calculated. These evaluations are imperative for the SLP to assess communication and language development of the children with CP.

Non-verbal communication can be assessed from gestures, facial expressions and vocalisations in response to age- appropriate questions asked, and verbal

communication comprising of speech and language needs to be assessed using formal and informal assessment procedures. There are assessment protocols which are designed for nonverbal children like the Picture Test of Receptive Language by Kaul (1999) which tests receptive language upto 4 years of age. In case of non-verbal children, where it is difficult to gauge their comprehension formally, or as an adjunct to formal methods, an attempt may be made to do so by informal methods.

This could be done by attempting to understand their comprehension of humour by telling them funny stories and jokes appropriate to their chronological/ developmental age, and observing whether the child smiles or laughs at the appropriate junctures. The SLP or caregivers could also observe the expression in the child's eyes which may change with the content of speech. This may prove to be an important indicator of verbal comprehension. An effective way to train parents / caregivers can be to demonstrate language therapy sessions by an experienced SLP and train them to emulate the clinician in extra clinical settings and thus be proxy clinicians. Herewith is presented some tips as to language and speech stimulation by caregivers.

### **Intensive language stimulation**

- **Use child-directed speech-** While speaking to the child with CP, the caregiver needs to use short phrases, constant repetition, using varied intonation patterns, recasting utterances.

For example, 'Who has come? Papa has come. Rohan's Papa has come. What has Papa got for Rohan? Did you ask Papa what he got for you?'

- **Self Talk-** The caregiver tries to capitalise the child's attention on him/her, by speaking about the activity that the caregiver is engaged in, at that moment.

For example, 'Do you know what I am doing? I am making food for you' or 'See what I am doing. I am building this tower...Would you like to topple it down?'

- **Parallel Talk-** The care-giver speaks about the activity that the child is engaged in, at the moment.

For example, 'Oh, you are going out with Dadaji! So you have worn your shoes and taken your bag. Where are you going?'

- **Labelling objects around the house-** Each time the child is using objects, the caregiver should name them, thus familiarising the child with the labels. For example, 'This is Rohan's toothbrush.' 'Let's take Rohan's plate and sipper and keep it ready.'

- **Use of gestures-** The caregiver needs to speak using a lot of gestures so that the child begins to associate the spoken words with the gesture. Care needs to be taken to speak first while engaging the child's attention and then immediately after to use the gesture so that the child gets to process speech first and the gesture is used later to facilitate his comprehension.

## **ALTERNATIVE AND AUGMENTATIVE COMMUNICATION**



## APPROACH

Once speech and language stimulation has been tried intensively for a sufficiently long period and the child still does not show relative progress, then the SLP needs to work towards using use of low tech or high tech devices and strategies to further augment speech efforts or switch to a non-verbal approach or an alternative approach.

Thus, for the child who is severely disabled, augmentative and alternative communication (AAC) modes (low tech) may be used such as customised communication boards/ books. Caregivers could click pictures of the child's routine such as the child eating, dressing, playing etc as also the objects involved in his activities of daily living such as his clothes, shoes, plate, cup, bag, special chair etc. Pictures of child and his close family members could be taken too. These pictures could then be printed and laminated to an appropriate size and used to compile communication books for different situations such as for mealtimes, schooltime, playtime, etc. These communication books could be kept at hand so that the child could communicate his needs in the situation he is in, with the help of that respective communication book.

There are assistive devices which have pre-recorded messages and can be operated by a thump or customised to the motor response feasible for the child. The child could be taught Bliss symbolics wherein the child is taught the system and expresses through pointing with hand/ finger or head pointer. Presently, there are many high tech devices available which are computer aided wherein the child is taught to type on keyboard or operate customised light touch switches or any other means suited to child's motor abilities. There are text-to speech options wherein the child may type words but that are synthesized into speech output.

## MANAGEMENT OF BREATHING DISORDERS FOR IMPROVING SPEECH BREATHING

The exercises which enhance breathing in general also help in improving speech breathing and should be continued for this purpose as well. Some other exercises may help in this aspect too and are given below:-

1. **Blowing exercises :-** The child should be encouraged to blow a lit candle from a few inches from child's face and then to do so with gradually increasing distance.

The same can be done with blowing off bits of paper and the caregiver could increase the level of difficulty by increasing the distance of paper bits from child or increase thickness of paper bits. Another variation of the same function to maintain child's interest is to blow bubbles and the caregiver could compete with child wherein he/she could demonstrate what is expected from the child by blowing for a longer time thus shown by the increased number of bubbles and the child is motivated to imitate that model.

2. **Free Phonation :-** The caregiver should encourage the child to say 'a.....' for as long as he can and keep count of how many seconds the child could phonate.

The child should be encouraged for his effort and further motivated to continue longer if he can. His efforts need to be reinforced with a reinforcer such as a sweet, smile or a hug or verbal praise which will motivate him to try harder.

3. **Counting :-** The caregiver could make a verbal child count whilst maintaining his intelligibility and the same level of loudness and pitch. So if initially he can do so till a count of 5, the child is encouraged to continue till 7 in the next effort and then till 10 and so on. The child could say days of the week and months of the year too in a similar manner and the word count is documented.
4. **Increasing length of utterance:-** In case of the verbal child, the caregiver should encourage the child to have an increased length of utterance while maintaining the same quality of speech in terms of loudness and pitch.
5. **Biofeedback:-** Whenever feasible, the child could be given biofeedback in terms of loudness and pitch characteristics such as with a recorded sample played back to child wherein the child is made to identify his fluctuations in voice.

## MANAGEMENT OF VERBAL COMMUNICATION/SPEECH DISORDER:

The objectives of therapy are to familiarise the caregivers to the concepts of intelligibility, naturalness of speech and comprehensibility.

Intelligibility means that the child's speech has to be clear enough for it to be understood by his listeners. Once that is achieved, the SLP needs to focus on the naturalness of child's speech which may sound strained, strangled, soft or too loud, hypernasal or with misarticulations and distortions in speech. The SLP needs to ensure that his speech sounds as natural as possible within the constraints of his impairment, in terms of the respiratory effort, voice, resonance, articulation and prosody (rate, stress, intonation).

Another focus is comprehensibility. This means that the onus for understanding does not lie on the child alone but also on the listener to understand as best as he/she can from the child's speech attempts, by training his own listening and guessing skills as to content of the child's speech even if it is not very intelligible. The caregiver could also improve the medium of communication such as by going closer to the child, or by reducing ambient noise in the room by turning off the TV while the child is speaking or encouraging the child to use an augmentative device such as a microphone to amplify his speech in case of limited loudness of voice. The listener could also give the child feedback about message being unintelligible and ask related questions to facilitate understanding.

### *To improve voice quality/reduce strained vocalizations*

- Gently massage the laryngeal area.
- If possible use blowing instruments to produce sound,

- Use appropriate posture to facilitate voice production.
- Encourage the child to laugh. Gentle stroking or tickling over the ribs will produce reflex laughing.
- Imitate child's vocalizations and encourage him to continue.
- Record child's vocalizations and play them back to reinforce his sound making efforts.

**Encourage babbling-** The child can be encouraged to repeat Consonant Vowel (CV) sequences after the caregiver for example, 'Ba ba ba ba' or 'Da da da da'. This may help to facilitate babbling which is a milestone in speech development a child typically goes through between 6-9 months of age.

**Encourage imitation of speech sounds-** When the child can imitate CV sequences, the caregiver can modify them to include different speech sounds like 'ka ka ga ga', or 'ma ma da da'. This could be followed by imitation of animal sounds, like 'Meow meow' or vehicle sounds, like, 'Drrr Peep peep Pom Pom'

**Imitation of simple words-** The caregiver could encourage the child to imitate simple words like Mama Papa, Bikki, Tata...comprising a functional vocabulary consisting of kinship terms, edibles, objects of his need, play and interest, objects around the house, names of favourite cartoon characters, etc.

**Encourage two word phrases-** once child is able to communicate at word level the caregiver could combine two words to form short phrases such as, 'Rohan's mummy'(Agent object), 'Rohan come (Agent action)' 'Throw ball(Action object)'

Encourage small sentences- Once child starts using small phrases, the caregiver can facilitate simple sentence structure like, 'Rohan wants to eat', 'Doggie says bow bow'.

Many children with CP may have severe expressive disorders. The techniques such as **Modelling, Shaping, Chaining, Prompting and fading** etc. could be used too.

Many may be able to comprehend spoken language age appropriately or with some lag from that of peers. Others may benefit from intensive therapy and learn to speak or use communication devices. As in all cases, early intervention is the key to success along with concerted efforts from rehabilitation professionals and caregivers to bring out the best participation of children with CP in their environment by improving functioning and reducing participation barriers.

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## 22. Cerebral Palsy: Meeting Nutritional Needs

### Intervention

A number of feeding and oral-motor intervention strategies have been developed to address difficulties with sucking, chewing, swallowing and improve oral-motor skills.

Strategies include oral sensorimotor management, positioning, oral appliances, food thickeners, specialized formulas, and neuromuscular stimulation. These interventions address different aspects of feeding difficulties, reflecting the range in specific problems associated with feeding and nutrition in CP. Sensorimotor techniques seek to strengthen oral-motor control and counteract abnormal tone and reflexes to improve oral feedings, and typically require months of daily application. Positioning techniques address poor postural alignment and control that exacerbates swallowing difficulties and include stabilizing the neck and trunk. Positioning interventions are individualized and often guided by video-fluoroscopy to optimize swallowing. Oral appliances have been used to stabilize the jaw, improve sucking, tongue coordination, lip control, and chewing. Multiple approaches may be used in children with growth failure.

*Nutritional intervention* is individualized according to the type and extent of dysfunction. Vitamin and mineral supplementation may be necessary. If chewable supplements are not handled safely, liquid forms may be added to acceptable foods. It is important to ensure that the diet remains palatable and nutritionally adequate by changes in food consistency to mechanically soft or pureed consistency. Presented with small, frequent meals they should be encouraged to eat more. Swallowing can also be improved by emphasizing the taste, texture and temperature of foods. Juices can be substituted for water and provide flavor, nutrients and calories. A cool temperature facilitates swallowing; therefore cold food items may be better tolerated. Sauces and gravies lubricate foods for ease in swallowing and can help prevent fragmentation of foods in the oral cavity. Moist pastas, rice and egg dishes are well tolerated. Avoid foods that crumble easily in the mouth, as they can increase the risk of choking.

## Determining nutritional needs

Determining energy needs may be complicated in children with cerebral palsy due to decreased physical activity and decreased caloric need in some children and increased caloric need due to the presence of spasticity, seizures, constipation, drooling and/or excessive sweating in others.

Nutrient needs of infants reflect rates of growth, energy expended in activity, basal metabolic needs & the interactions of the nutrients consumed.

### Theoretical approach:

#### 1. *Energy/Calories:*

Include dense caloric foods like smoothies/sheera/porridge/ milkshakes with milk fortified with dry milk powder, puddings, custards, sugar, honey, jelly, fruit pulps, cereal and fruit combination, amylase rich food preparations in your child's diet to meet their requirement because of feeding difficulties. The goal is to add calories without adding bulk (roughage) or empty calories in diet.

#### 2. *Protein:*

It is needed for tissue replacement and its growth (as in stem cell transplantation), deposition of lean body mass. Infants require a larger percentage of total amino acids.

Human milk or infant formula provides the major portion of protein during the first year of life. At the end of the 6 months, diets of infants with cerebral palsy should be supplemented with additional sources of high quality protein such as yoghurt, strained meats or formula feeds along with human milk. (e.g.; lean meats, eggs, milk and its products like paneer, yogurt, cheese, lentils and legumes)

Infants may receive inadequate amounts of protein if their formula is excessively diluted

Minimum acceptable levels of intakes of recommended dietary allowances (2010) as per age for Energy and protein for infants, children with CP are as follows:

**Table 1: Recommended daily dietary allowances for children with cerebral palsy**

AGE	BODY	WEIGHT (kg)	ENERGY (kcal)	PROTEIN (gms)
INFANTS	0 – 6 months	5.4	92/kg	1.16/kg
	6 – 12 months	8.4	80/kg	1.69/kg
CHILDREN	1 – 3 yrs	12.9	1060	1607
	4 – 6 yrs	18.0	1350	20.1

	7 – 9 yrs	25.1	1690	29.5
BOYS	10 – 12 yrs	34.8	2190	39.9
GIRLS	10 – 12 yrs	35	2010	40.4
BOYS	13 – 15 yrs	47.6	2750	54.3
GIRLS	13 – 15 yrs	46.6	2330	51.9
BOYS	16 – 17 yrs	55.4	3020	61.5
GIRLS	16 – 17 yrs	52.1	2440	55.5

### 3. Fats (lipids):

60% of brain's dry weight is fat and under normal conditions 25 % of this fat is DHA (docosahexanoic acid), an omega 3 fatty acids. It has been found to have unique, important and interchangeable contribution to overall brain and nervous system functioning. DHA is the brain's building block and has neuroprotective (antiinflammatory) effect because of its ability to raise the seizure threshold of the nervous system. They are the concentrated source of energy. Significantly low fat intakes may result in inadequate total energy intake. Omega 3 and omega 6 long chain polyunsaturated fatty acids are important for neural tissues and its development. e.g.: Almonds, walnuts, olive oil, mustard oil, canola oil, flaxseeds, cod liver oil/fish oil.

It is also possible to purchase supplements of Docosahexaenoic acid (DHA), an Omega – 3 fatty acid, obtained from marine algae.

### 4. Water:

Requirement of water is as follows:

**Table 2: Water requirement for the children according to the age**

AGE	WATER REQUIREMENT (ml/kg/day)
10 days	125 – 150
3 months	140 – 160
6 months	130 – 155
1 year	120 – 135
2 year	115 – 125
6 year	90 – 100
10 year	70 – 85
14 year	50 - 60

(From barness LA: Nutrition and nutritional disorders. In Behrman RE, Kliegman RM: Nelson textbook of pediatrics, ed 17, Philadelphia, 2003, saunders)

## **5. Vitamins & Minerals:**

Supplementation of vitamins and minerals should be prescribed only after careful evaluation of infant's/child's intake. Commercially prepared infant formulas are fortified with all necessary vitamins, therefore formula fed – infants rarely need supplements.

Regular exposure to sunlight for 30 minutes/week has been reported to be sufficient to meet vitamin D, and /or supplementation is recommended to prevent from osteopenia/osteoporosis. Vitamin D is found in egg yolk, liver, oily fish, fortified milk or spreads. Calcium rich foods include milk, cheese, yogurts, milk puddings, fish and sesame seeds/paste.

Magnesium, folic acid, vitamin B6 & B12 is required for building muscles, bones and other organs, synthesis of cells. Children with CP need a balanced supplement containing the vitamin B complex with Vitamin C, so as to ensure regular intake of these important micronutrients.

The incidence of iron deficiency in child with CP is quite high. Hence include iron rich food sources like non-vegetarian foods like lean meat, garden cress seeds (halim), pressed rice (poha), green leafy vegetables, sesame seeds, fortified cereals, etc. In addition, iron found in plant foods contains more inhibitors of iron such as phytates, calcium and fiber. Vitamin C found in fruits and vegetables enhances iron absorption and reduces the effects of phytate and hence should be consumed along with iron rich foodstuffs.

## **6. Fiber:**

Low fiber foods tend to cause the most trouble with constipation, such as highly processed snack and junk foods, fried foods, too much red meat, ice cream. These foods are also low in nutritional value and should be replaced with healthy alternatives that provide important fiber, vitamins and minerals. Include high fiber foods in soft form like, whole grain cereals and pulses, fruits and vegetables (green leafy veggies). An increase in fluid intake can improve symptoms. It can be difficult to achieve sufficient fluid intake when thickened fluids are advised. Your dietician can advise whether sufficient fluid and fiber are being consumed. Even offering 2 – 3 mouthfuls of liquid every hour will go long way to achieving adequate hydration to manage constipation. Daily physical activity can help, including use of stander, walker, following a physio programme.

## **7. Pre and Pro-Biotic:**

Make pre and pro biotic a regular part of the diet to help build healthy bacteria in the gut and help relieve constipation. E.g.: yogurt (freshly prepared, 4 hourly set curd), Yakult drink or commercially available supplements.



## **8. Nutritional support (Tube Feeding):**

For children with moderate to severe aspiration, frequent coughing, choking or malnutrition related oral-pharyngeal dysphagia and GER, tube feeding may be necessary or surgical interventions with gastrostomy (tube feeding directly into the stomach) or jejunostomy tubes (tube feeding into the middle portion of the small intestine, the jejunum) and antireflux procedures are often deemed necessary to improve nutritional status and reduce risk of chronic aspiration.

The child with a temporary feeding tube can be fed by tube at night, allowing hunger and thirst to occur during the day so that oral feeding can be continued. This may also be a time that oral motor skills to improve oral feeds may be optimized, allowing a better transition back to oral feeding.

The multidisciplinary involvement of feeding specialist, who may be occupational therapist or speech therapist depending on location, gastroenterology and/or pediatric surgery for consideration of tube placement and nutrition is suggested.

### **A. Practical approach:**

#### **Nutrition in lifecycle**

##### ***0 – 6 Months:***

Human milk: it is unquestionably the food of choice for infants. Its composition is designed to provide the necessary energy and nutrients in appropriate amounts.

If sucking is a problem, human milk can be expressed by mothers in many ways like manual expression, battery operated pump, electric pump. Breast milk can also be stored by refrigerating or freezing it.

Formula feeds to infant can be given if breast feeding is contraindicated. For e.g. Pre Nan, Nan pro1, Lactogen 1, Nestum 1, etc. Many mothers may also choose to offer a combination of breast milk and formula feedings.

##### ***6 – 12 Months and on:***

Continue breast feeding. Start the weaning process by supplementing foods like mashed potato, mashed bottle gourd (doodhi), banana, stewed apple, khichdi (med) with addition of little ghee (clarified butter), butter and progressing to normal table foods consisting of cereals, pulses, whole milk, yogurt, cheese, meat, fish poultry, fruits and vegetables in the form preferred by the child. Commercial Infant Formulas are available too, e.g. Cerelac, Isomil, Nan pro 2 to 4, Lactogen 2 to 4, Nestum 2, to supplement the weaning foods.

The sequence in which these foods are introduced is not important; however it is important that one single ingredient food be introduced at a time. Introducing a single new food at a time at 2 – 7 days interval enables parents to identify any allergic response or food intolerances. Introducing vegetables before fruits may increase vegetables acceptance.

Infants demonstrate their acceptance of new food by slowly increasing the variety and quantity of solids they accept. Parents who thoughtfully offer a variety of nourishing foods are more likely to provide a well balanced diet and help their children learn to accept more flavors. To add variety to an infant's diet, vegetables and fruits can be added to cereal feeding. It is important to offer various foods and not allow the infant to continue consuming a diet consisting of one or two favorite foods. Older infants generally reject unfamiliar foods, the first time they are offered. When parents continue to offer small portions of these foods without comment, infants become familiar with them and often accept them. When offering a new food, caregivers/parents need to be willing to provide 8 – 15 repeated exposures to enhance acceptance of that food.

### *Serving size:*

The size of a serving of food offered to a child is very important. All one year infants eat one third to one half the amount an adult consumes. This proportion increases to one half an adult portion by the time the child reaches 3 years of age and increases to about two third by 6 years of age. A Tablespoon (Tbsp), not a heaping tablespoon of each food for each year of age is a good guide to follow.

An important part of the treatment is helping the patient get adequate nutrition, while protecting against complications such as pneumonia from food or liquid getting into the lungs. Obviously, this requires a specialized diet (ground/mechanical soft diet with thickened liquid).

There are five different diet levels from *pureed (level 1)* up through *modified regular food (level 5)*. The diets vary in texture and consistency, and are chosen depending on which would be most effective for a specific patient.

### *Level 1*

**Pureed Foods:** foods in this group are pureed to a smooth, mashed potato like consistency. If necessary, the pureed foods can keep their shape with the addition of a thickening agent. E.g.: meat is pureed to a smooth pasty consistency. Hot broth or hot gravy may be added to the pureed meat, approximately 30 ml of liquid per 90 ml of serving of meat.

- Pureed meats, poultry and fish
- Pureed scrambled eggs & cheese
- Thinned cooked cereals (no lumps)
- Baby cereals ( cerelac stages 1 & 2)
- Mashed potatoes
- Pureed dals
- Pureed vegetables and fruits
- Creamed soups or vegetable soups
- Pureed cottage cheese(paneer)

- Thickened milk or eggnog, plain yogurt
- Smooth puddings, mousse, custards, cream
- Sugar, syrup, honey, jelly
- Thickened juices & nectars
- Formula feeds like, pediasure, neogain, fit kid powder, ketocal, peptamen junior, protein x junior, isomil etc.

### *Level 2*

**Minced foods:** foods in this group should be minced/chopped into very small pieces (1/8 inch). The flecks of food are similar in size to sesame seeds (til seeds)

- Minced meat, fish , poultry
- Minced soft cooked, scrambled, poached eggs
- Minced soufflé and omelet
- Cooked cereals and pulses (minced)
- Minced vegetables
- Minced/stewed fruits
- Semi thickened juices
- Cottage cheese
- Milkshakes
- Puddings, including rice and tapioca

### *Level 3*

**Ground foods:** foods in this group should be ground or diced into ¼ inch pieces. These pieces of food are similar in size to rice.

- Ground meat, fish, poultry
- Scrambled eggs, poached eggs
- Cooked cereals and pulses/lentils
- Ground well cooked vegetables
- Smooth fruited yogurt

### *Level 4*

**Chopped foods:** foods in this group should be chopped into ½ inch pieces. These pieces of food are similar in size to uncooked elbow macaroni or croutons (small bread crumbs)

- Chopped meat, poultry
- Any egg preparations
- Noodles, pastas, spaghetti, toast
- Chopped cooked vegetables

- Soft, dry cereals
- Chopped fruits

### **Level 5**

**Modified regular foods:** foods in this group are soft, moist, regularly textured food

- Soft moist meat, fish, poultry
- Soft breads, crackers
- Cakes, doughnuts
- Soft cooked vegetables
- Soft cooked cereals and pulses/lentils

*It is vital to seek referral to dietician when a modified consistency diet has been recommended, as modifying the consistency of foods can dilute the nutrient value of a meal, leading to weight loss or malnutrition. Your dietician can advise you on ways to maximize the nutrient value of each meal.*

### **Ketogenic diet:**

The ketogenic diet is a high-fat, adequate-protein, low-carbohydrate diet that in medicine is used primarily to treat difficult-to-control (refractory) epilepsy in children. The diet forces the body to burn fats rather than carbohydrates. Normally, the carbohydrates contained in food are converted into glucose, which is then transported around the body and is particularly important in fuelling brain function. However, if there is very little carbohydrate in the diet, the liver converts fat into fatty acids and ketone bodies. The ketone bodies pass into the brain and replace glucose as an energy source. An elevated level of ketone bodies in the blood, a state known as ketosis, leads to a reduction in the frequency of epileptic seizures.

The original therapeutic diet for pediatric epilepsy provides just enough protein for body growth and repair, and sufficient calories to maintain the correct weight for age and height. This classic ketogenic diet contains a 4:1 ratio (although a 3:1 ratio has also been used) by weight of fat to combined protein and carbohydrate. This is achieved by excluding high-carbohydrate foods such as starchy fruits and vegetables, bread, pasta, grains and sugar, while increasing the consumption of foods high in fat such as nuts, cream and butter. Thus, an individual's diet is composed of 90% and 86% of calories coming from fat, respectively

Implementing the diet can present difficulties for caregivers and the child due to the time commitment involved in measuring and planning meals. Since any unplanned eating can potentially break the nutritional balance required, some people find the discipline needed to maintain the diet challenging and unpleasant.

\*Remember that ketogenic diet has to be closely monitored by the specialist. It is best to consult a nutritionist as diet plans are individualistic and should be specially designed to cater to the needs of the child.

## **Special considerations**

The following are some general guidelines for safe swallowing. Remember that CP children have individual requirements, so all of these guidelines may not apply to every child.

Maintain an upright position (as near 90 degrees as possible) whenever eating or drinking.

Allow them to eat slowly, by offering small bites – only ½ to 1 teaspoon at a time.

When one side of the mouth is weak, place food into the stronger side of the mouth. At the end of the meal, check the inside of the cheek for any food that may have been pocketed.

Try turning the head down, tucking the chin to the chest, and bending the body forward when swallowing. This often provides greater swallowing ease and helps prevent food from entering the airway.

Do not mix solid foods and liquids in the same mouthful and do not “wash foods down” with liquids, unless you have been instructed to do so. Feed them in a relaxed atmosphere, with no distractions. Following each meal, make them sit in an upright position (90 degree angle) for 30 to 40 minutes. Sometimes, making just one small tweak can change the entire flavor profile and turn a tolerable food into a delicious one. Remember to start slow and over time increase the amount of veggies in smoothies and foods. Making slow changes can help change the palate to tolerate a greater amount of healthy food as well as give the digestive system time to adjust to a new diet.

- Try to ensure that you separate out the different tastes as your child grows.
- There are techniques you can use to help the development of chewing such as offering dried apricots or fruit straps in between meals. For children who would find these difficult you can still encourage the chewing reflex by allowing them to chew on (but not swallow) a piece of fruit securely wrapped in a piece of muslin which you can control so that they do not need to deal with the swallowing of solid food.

To sum up, make sure that your child has a good balanced diet with proteins (found in meat, cheese or beans) carbohydrates (found in potatoes and bread), roughage (found in oats, wheat germ and green leafy vegetables), fats (found in butter and oil), vitamins and minerals (found in fruit and vegetables), and plenty of fluids. You should be advised by a dietician about the amount of calories your child should receive for his/her weight. If it is difficult to provide enough in the normal way, you could consider adding food supplements or fortified drinks to their diets.

## Nutritious Recipes

### AMYLASE RICH FOOD

You can use any cereal and pulse or its combination to make this recipe. It is calorically dense and easy digestible. The bioavailability of that particular food stuff increases with this method.

Soak rice/moongdal/ragi/bajra in water overnight. Drain the water, spread the grains on a plate and allow it to germinate by covering with a damp cloth for one day. Dry the germinated food item in sun and roast till it develops a malted flavor. Powder and store in air tight tin.

### WHEAT GRAM PORRIDGE

#### *Ingredients:*

- Roasted wheat flour – 25 gm
- Powdered, roasted bengalgram – 15 gm
- Powdered, roasted groundnut – 10 gm
- Sugar or jaggery – 30 gm
- Spinach (or any green leafy veggies) - 30 gm

#### *Method:*

Roast groundnut, wheat and bengalgram and powder them

Mix the wheat, bengalgram and groundnut powders and prepare a batter by addition of jiggery, dissolved in a suitable amount of water.

Boil spinach in water till soft, mash and strain.

Add the vegetable juice to the batter and cook for a few minutes with continuous stirring till semisolid.

### BAJRA KITCHERI

#### *Ingredients:*

- Bajra\* – 40 gm
- Greengram dal – 20 gm
- Carrot \*– 20 gm
- Oil – 5 gm

*\*Instead of carrot, pumpkin, sweet potato or other vegetables can be used*

*\*Instead of bajra, jowar can also be added*

#### *Method:*

Grate carrot

Boil dal till half done.

Add bajra to the boiled dal, carrot and salt and mix well.  
 Cook till the grains become soft  
 Remove from the fire and season with jeera and oil. Blenderise it

### **PRESSED RICE PORRIDGE**

#### ***Ingredients:***

Pressed rice – 35 gm  
 Roasted bengalgram dal – 25 gm  
 Sugar or Jaggery – 25 gm

#### ***Method:***

Powder pressed rice, roasted bengalgram dal and sugar and mix the powder.  
 Add hot water to make the mixture soft in consistency to form porridge.

### **MILLET PORRIDGE**

#### ***Ingredients:***

Roasted Ragi powder, dehusked – 30 gm  
 Roasted greengram dal powder or lentil – 15 gm  
 Roasted groundnut powdered – 10 gm  
 Spinach (or any leafy vegetable) – 30 gm  
 Sugar or Jaggery – 20 gm  
 \*Ragi can be replaced by clean dehusked jowar, bajra, rice or any other millet.

#### ***Method:***

Boil the leafy vegetable in water till soft, and mash/puree  
 Add the millet, pulse, groundnut powders to the vegetable juice.  
 Add jaggery and cook for few minutes to a soft consistency

### **MAIZE PUTTU**

#### ***Ingredients:***

Broken maize: 35 gm  
 Redgram dal (powder): 25 gm  
 Jaggery: 25 gm

#### ***Method:***

Roast broken maize and redgram dal and powder them.  
 Dissolve jaggery in water and strain through sieve or cloth.  
 Prepare a batter of the maize and dal powder with the jaggery syrup.  
 Steam- cook the batter like idli

## 23. Psychological Intervention

Education and vocational preparation come into the foreground by school age. During this crucial period, concerns about the physical disability should not distract attention from the emotional and social needs of childhood and adolescence. Disabled youngsters need the same variety of life experiences as all other children, to develop emotional flexibility, personal determination, and social skills. As a child with cerebral palsy grows older, the need for different types of therapies and support services will also change. Psychological interventions for children with cerebral palsy are aimed at obtaining early diagnosis of co-morbidities and therapies.

### **Diagnosis of psycho-motor and psycho-social development:**

- Assessment of the actual development in terms of deficits of fine motor skills, perceptive development, social development and independence
- Assessment of interaction between mother and child aged 0 to 3 years of age
- Assessment of the level of the deficit manifestation in terms of neurological diagnosis

### **Psychological assessment:**

- Cognitive processes: attention span, memory, thinking, intellect
- Assessment of fine motor skills
- Assessment for school maturity
- Assessment of brain functions - gnosis, praxis, speech
- Assessment of the emotional and behavioural state of the child
- Personality assessment

The assessment process differs from an individual to individual and the nature and severity of the case. The assessment process usually lasts for about 45 minutes and if needed then it is held in several sessions. The final medical report includes the test results and other relevant observations made during the examination. Note: The methods and length of assessment are based on the psychological age and capabilities of the child.



**Therapeutic Interventions:** Below mentioned are list of therapies for individuals with cerebral palsy:

1. *Neuro-cognitive therapy:*

This is a new approach to treating individuals with cerebral palsy. It is based upon two proven principles:

- ii) **Neural Plasticity:** The brain is capable of altering its own structure and functioning to meet the demands of any particular environment. Consequently if the child is provided with an appropriate neurological environment, he will have the best chance of making progress.
- iii) **Learning:** Lev Vygotsky proposed that children's learning is a social activity, which is achieved by interaction with more skilled members of society. Counseling and behaviour therapy, for emotional and psychological challenges may be needed at any age, but is often most crucial during adolescence.

2. *Cognitive Rehabilitation Therapy (CRT):*

Children with cognitive impairments face tremendous levels of uncertainty and frustration, thus in need of additional support. As a parent it is very important that you should learn the best ways to interact with your child as this can immensely beneficial as the child grows up.

Cognitive rehabilitation is a program of guided therapy to learn (or relearn) ways to concentrate, remember and solve problems after an illness or injury affecting the brain. It is a structured set of therapeutic activities designed to retrain an individual's ability to think, use judgment and make decisions.

The focus is on improving deficits in memory, attention, perception, learning, planning and judgment. There are many intervention strategies and techniques used to help children reduce, manage or cope with cognitive deficits. The desired outcome of cognitive rehabilitation is an improved quality of life or an improved ability to function in home and community life.

Cognitive rehabilitation techniques are restorative training or re-training the brain in normal function or compensatory ways. This technique teaches the child to make use of tools to help make up for the deficits.

The goal of cognitive rehabilitation is to improve cognitive abilities in order to obtain as much independent functioning as possible. Some of the specific benefits of cognitive rehabilitation include improvements in the following deficits:

- Attention span
- Memory
- Problem - solving
- Visual - spatial relations
- Learning functional tasks such as feeding, dressing, etc.



Figure 1



Figure 2



Figure 4



Figure 5

Cognitive rehabilitation may be performed in conjunction with or as part of other therapies, such as behavior, occupational or speech therapy.

Cognitive rehabilitation may be performed by a variety of professionals, such as neuropsychologists or psychologists. The nature of the condition and the specific cognitive deficits determines what kind of specialist would be needed.

There are two treatment approaches to cognitive rehabilitation:

- i) **Restorative approach:** This is based on the theory that repetitive exercise can restore lost or under developed functions. Some methods and techniques include:
  - Auditory, visual and verbal stimulation and practice
  - Number manipulation
  - Computer - assisted stimulation and practice
  - Behavior modification
- ii) **Compensatory approach:** This method strives to develop external assistance for cognitive deficits. Compensatory cognitive rehabilitation may use the following techniques:

- Employing visual cues, written instructions, memory notebooks, watches, beepers, computers and other electronic devices to trigger functional behaviors.
- Simplifying complex tasks, capturing the patient's attention, minimizing distractions and teaching self-monitoring procedures.

The compensatory approach to cognitive rehabilitation has been more widely accepted than the restorative approach, but these approaches are not mutually exclusive. Many therapeutic programs employ elements of both.

A few cognitive rehabilitation therapy strategies for children with cerebral palsy that can be practiced at home by parents are mentioned below:

- Many children with cerebral palsy have cognitive impairments and they have difficulty maintaining their attention span on the activity or when they are being spoken to. Designate a separate room or a part of a room that is his special area. Avoid brilliant colors or complex patterns in decor. Simplicity, solid colors, minimal clutter, not near a window, proper lighting and a worktable facing a blank wall away from distractions will help to increase attention span and concentration.
- Make use of visual cues like flashcards to teach as this would help the child have clear concept formation.
- Due to physical limitations many children have difficulty writing and producing good, legible handwriting and repeated practice would only frustrate your child. Try and make writing enjoyable by making use of paints, crayons, sand, etc. You can also make use to computers, magical pens and white boards to improve the handwriting and make the activity more interesting.
- There is wide range of educational audio visual CD's available in the market which can be used to teach the child concepts like colours, shapes, fruits, body parts, daily activities of living, etc.
- Modify the homework and class work assignments for the child, according to his or her functioning and the possible barriers which could restrict his development.
- Expose the child to new learning opportunities (Refer)

Figure 1 - Cognitive Rehabilitation

Figure 2 - Cognitive Rehabilitation

Figure 3 - Cognitive Rehabilitation

Left untreated, a child may become isolated, have counter-productive interactions, and experience peer rejection. These can lead to lower academic performance, social-emotional deficiencies, and attention deficits. If a child exhibits, the above mentioned signs then its best to consult a psychologist.

### **3. Behaviour therapy:**

This therapy is often used to enhance child's ability and discourage destructive behaviours. As symptoms of cerebral palsy can cause behavioural and emotional problems, many children benefit from counseling or behavior therapy. Behavioural therapy utilizes psychological techniques to improve physical, mental, and communicative skills. The activities used may vary greatly according to age and disability of the child. Some techniques will be used to discourage destructive behaviour whereas the others to encourage self-sufficiency. Ultimately, a behavioural therapist will act as a coach to the patient and family, by suggesting ways to improve behaviour, as most of the work will be done at home.

Behaviour therapy can complement physical therapy, as employing psychological techniques that encourage the mastery of tasks can promote muscular and motor development. Behavioral therapy can help alleviate depression, mood swings, sadness, loss, anger and frustration by allowing previous negative outcomes to be replaced with a more positive perspective. Praise, positive reinforcement, and small rewards can encourage a child to learn to use weak limbs, overcome speech deficits, and stop negative behaviors like hair pulling, throwing temper tantrum, etc.

Living with a disability, no matter what the severity, can feel like a limitation to the disabled person. It is for this reason that individuals, especially children who are subjected to the limitations of a disability from early on in life, can at times develop negative behavioral traits that may further affect the person's ability to live life fruitfully and independently. It is in such conditions, in which the person's quality of life is being affected or they are affecting the environment around them that behavioural therapy can be so valuable. Even in situations where no such personality traits have surfaced, behavioural therapy is an important part of a child's ongoing therapeutic schedule.

In cases involving behavioural therapy, the treatment is aimed at helping them not only become more independent and productive, but also more able to function in everyday life. For instance, in physical therapy the therapist will help the child to learn to walk with more ease by walking with them, or pick things up with more ease while helping their muscles develop, while in behavioral therapy the therapist might put an object of interest, perhaps a toy or a piece of candy, into a box. They will then request that the child with cerebral palsy to reach into the box with his or her weaker hand. It is the reward aspect of coaching the child to use his or her weaker hand that connects with his or her mind.

A few behaviour therapy strategies for children with cerebral palsy that can be practiced at home by parents are mentioned below:

1. First develop a consistent behavioral management plan to use with your child when appropriate or inappropriate behaviors are exhibited. This could mean allowing the child to play with his favorite toy when he displays desired behaviour or giving a time -out when the child displays inappropriate behaviour.

2. Use a reward system to provide motivation to your child for displaying good behaviors and tasks completed. Set up a clear system of rewards like sticker charts, gold stars, non-edible treat such as toys so that the child knows what to expect when they complete a task or refine their behavior.
3. Praise your child for good behaviors rather than only giving time-out or shouting, when he /she displays bad behaviours. This will help your child develop feelings of self-worth and will build upon his / her confidence level.
4. The child should be taught constructive and acceptable ways to vent out physical or verbal aggression. For example: either drawing, painting, playing a musical instrument like drums, practicing breathing exercise when he or she is angry or frustrated.
5. Many children with cerebral palsy become over stimulated in a crowded, noisy environment, which can lead to meltdowns. Learn to recognize what external triggers lead to undesirable behavior in your child, and remove her from those situations. You can help the child by removing the child from the over-stimulated environment or teach the child to calm himself or herself down in such situations.
6. As children with cerebral palsy have limited exposure to socializing due to their physical condition they need to be taught skills to socialize. Techniques such as modeling, role playing and skills training can be conducted with the child as this will give the child a clear ideas as to what constitutes in socially adaptive behavior.
7. Re-evaluate your family's communication methods if your child seems to be unusually frustrated by the inability to express himself/ herself. Perhaps purchasing a communication board that allows the child to type out his thoughts or point to words can help.
8. Get your child into therapy with a behavioral specialist if you have tried other options and problem behaviors still exist. A professional therapist can help your child sort through his feelings, become better at communicating his wishes and feel better about himself/ herself.

#### **4. Counseling or Talk Therapy:**

As they get older, children with cerebral palsy will likely feel disliked by their peers, isolated from friendships, embarrassed by body image and/or frustrated with treatment goals. This may be a good time to introduce them to "counseling" or "talk therapy," where they can talk about the things that are bothering them and learn to put them in perspective. It differs from behavioral therapy in that the goals are more along the lines of learning to accept and embrace one's individuality rather than of raw behavior modification.

Even the most "normal" young person faces daily psychological and emotional

challenges. Your hopes for your child at this age won't differ much from that of any other parent. You want your child to cultivate a healthy attitude toward his or her challenges and to acquire the basic tools that will carry them into adulthood. Many adolescents and teens see therapists to help process these complicated years.

The counselor will talk with his or her patient to help work through the emotional stresses that cerebral palsy can place on a child. Sometimes children with cerebral palsy can become violent or aggressive, resorting to things such as biting or hair-pulling to help release their anger. It is the job of the counselor to help the child find new ways to release their aggression and frustrations, either vocally or, if the child is able to control his or her hand enough, perhaps drawing or writing, with the aid of new computer technology that makes it possible for people with cerebral palsy to type and have full use of a computer. A counselor will be able to help your child see his or her situation in the best light, and hopefully help to alleviate many of the stresses that a child with cerebral palsy goes through. The right therapist can work wonders.

## **5. Aversion therapy:**

This therapy works on the principle to reward rather than punish negative consequences. This can help enhance self – esteem and the confidence level of the individual. For example, if a child is throwing temper tantrums and isn't cooperative during the therapy sessions then the parent or there therapist should not shout or get angry at the child. Rather the child should be rewarded if he or she moves in a positive direction for example; in spite of the temper tantrums if he is exercising then he or she should be praised and rewarded.

## **5. Group Therapy:**

Group psychotherapy is a process of psychological influence by verbal and non-verbal techniques in which the psychologist uses the interactions created in specially organized small groups of patients (mainly interactions of emotional character), in order to reduce the patients' body and nervous discomfort and to improve psycho-social functioning. Individuals with physical or cognitive limitations often face real, and sometimes self-imposed, challenges in building relationships. Difficulties in communicating, fitting in or feeling accepted can lead to delays in social, emotional and even physical development.

The group therapy is viewed as an important factor for individualization and socialization of children with cerebral palsy. The purpose of this method is to relieve patients and to develop their skills to solve problems as well to overcome noxious personal and behavioural stereotypes. Through group therapy children are able to acquire new knowledge, skills and good behaviour. The group rehabilitation and therapy depends on the specificity and psychological development of children within the group.

## **6. Caring for Caregivers:**

The family is considered to be a system of continuous process with different behavioural models. Not only does cerebral palsy alter the emotional dynamics between your child and you, but it also stresses the emotional dialogues between you and your family. We believe parents and the family members have to be emotionally prepared to accept the diagnosis and to carry their child through this “special” journey. You must understand and see the “special” needs of their child. Devoted support from caregivers (you and the family members) is crucial for an improved quality of life and attempting to normalize this “given” situation.

### **Strategies for parents to cope with the situation:**

- i) Ask for help if it's difficult caring for your child. For example: Hiring a maid makes more sense than wasting time into household work, rather you could invest that time into teaching your child or may be time for yourself like exercising.
- ii) Make use of the school hours for meeting your relatives, family members or friends while the child is away. Plan quality time together with your spouse for example; lunch with him when your child is at the school.
- iii) Do not feel guilty about the break and try to remind yourself that it will help you to be renewed for the things you need to do when you get back. Try and schedule your time in such a way that you are left with sometime for yourself. If possible, take time off and go for shopping or to the parlor, visit a friend, etc.
- iv) It is very important that you talk about your feelings and emotions that you are going through. It is important to vent out your thoughts at regular interval of time. Especially someone who just listens could be a great source of strength.
- v) If you feel that you are unable to cope up with things around and your stress or anxiety levels have increased or you are starting to show depressive symptoms (like crying spells, change in sleep or appetite, loss of interest, etc) seek help of a professional. Counseling session for you or your spouse or the entire family may help.
- vi) You could join support groups which are for children with autism and their parents. It may be helpful to listen or talk to people who have been or are going through a similar situation. Also, support groups could be a great source of information about the services available in your area or about the new possible treatment options available.

### **Figure 4 – Caring for Caregivers**

The principles of the family therapy are used during consultations with patients. The work is done with trained family therapists. The family will be informed about the confidentiality of the process.

- 7. Expressive therapies:** These are usually used with people who have difficulty

verbalizing their feelings such as art, music, poetry, etc which could help freeing and empowering oneself. Sometimes children with cerebral palsy can become violent or aggressive, resorting to things such as biting or hair pulling to they can be helped to release their aggression and frustrations, by either being vocal or, if the child is able to control his or her hand enough, perhaps drawing or writing.

**To conclude....**

Regardless of advancements in technology, a psychologist can have a profound impact on your child's life. Because cerebral palsy can so greatly affect a child's physical ability, the psychological health and development of the child is of least concern. However, a positive state of mind and outlook can lead to an improved quality of life and functioning.



## 24. Adaptive Devices

### ADAPTIVE AIDS:

- Adaptive Seating Chair (CP Chair): Since children with Cerebral Palsy often have problems with their posture and muscle tension, a chair may need to be adapted with creative use of foam for the child to sit comfortably. A CP chair varies in size and is customized for the particular child and gives an appropriate support for head, trunk, leg and arm support. Components include include the headrest, seat and back inserts, anterior and lateral trunk supports, wedge support, arm supports, and leg supports.

Good Sitting position: A good sitting posture has the head in slightly forward position, straight back without leaning on either sides of the chair, bottom supported on the chair with hip and knee bend and feet flat on the floor.

Figure 1: Correct Posture in sitting and seating chair measurement

- Adaptive Writing Devices, aids and paper:

Figure 2: showing adaptive writing devices.

- Railings along the staircase, classrooms and toilets.
- Adaptive Commodes:
- Schedule Boards, checklist timers, calenders.
- Adaptive Cushions: To prevent development of pressure sores due to asymmetric weight bearing, various cushions to give pressure relief are advice eg: air, gel and polyurethane foam cushions for seating.

### Wheelchair Prescription and Modification:

#### Advantages:

- To improve the mobility in moderate to severe cases.
- Increases the participation

An occupational Therapist is involved in assessment and provision of wheel chairs and also in training to use a wheelchair. An Occupational therapist also provides

with knowledge regarding the prescription and modification of seating cushions and postural supports to prevent skin breakdown / pressure ulcers, as well as type of controls to operate the wheelchair.

### **Assistive Devices and Assistive Technology:**

The Cerebral Palsy assistive technology includes hardware and software which helps maximize their abilities to access information and services. It has the potential to increase the abilities of person with disabilities and can lead to independent living.

- Typing Master Software
- Text to Speech Software
- Voice recognition computer applications
- On screen keyboard setting, Magnifier setting, Narrator setting, mouse keys utilization and setting.

The objective is to see how the technology can be used by a person with disabilities to enable him or her lead a more purposive life with some skills to do work and at the same time too have time for relaxing and enjoying life.

### **Some Assistive Technology used in Writing ( Figure 2)**

- Modulan grip aids

Figure 2: Various Grip Aids for writing

- Adapted paper(eg raised lines, highlighted lines. and so on)
- Slantboard for writing
- Type writer
- Portable word processor
- Computer
- Text to Speech Software
- Voice recognition computer applications.
- On Screen Keyboard setting, Magnifier setting, Narrator setting, Mouse keys Utilization and setting.

### **Alternate Computer Access**

- Keyboard with easy access or access DOS
- Keyboard
- Arm support ( eg:ergorest)
- Trackball , track pad, joystick with onscreen keyboard

- Alternate keyboard (eg: Intellikeys, Discover Board, TASH)
- Mouth stick or head pointer with standard or alternate keyboard.
- Head mouse or head master / tracer with onscreen keyboard.
- Switch with scanning
- Voice recognition software
- Word prediction (eg Co: Writer) to reduce keystrokes

### **Composing Written Material**

- Word cards, word books, or word wall
- Pocket dictionary or thesaurus
- Electronic or talking electronic dictionary, thesaurus, or spell checker ( eg: Franklin Bookman)
- Word processor with word prediction (eg: Co:Writer) to facilitate spelling and sentence construction
- Talking word processor for multisensory typing
- Voice recognition software
- Multimedia software for expression of ideas ( assignments)

### **Communication**

- Augmentative and Alternative Communication( AAC)
- Communication board or book with pictures, objects, letters, or words.
- Eye gaze boards ( Eye gaze communications)
- Simple voice output device ( eg Big Mack, Cheap Talk, Voice-in-a-Box, Micro Voice, Talking Picture Frame, or Hawk)
- Device with speech synthesis for typing (eg: Cannon Communicator, Link, Write: Out Loud with laptop computer)

### **Reading, Studying And Math**

#### **Reading**

- Changes in text size, spacing, color, or background color
- Use of pictures with text ( eg Picture It, writing with Symbols)
- Book adapted for page turning (eg page fluffers, 3 ring binder, cardboard in page protector)
- Talking electronic device to pronounce challenging words (eg: Franklin Bookman)

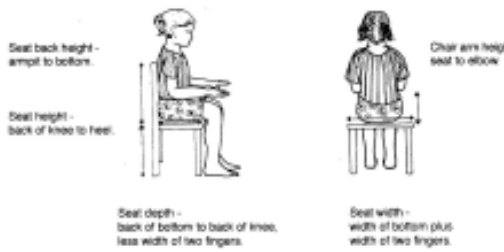


Figure 1

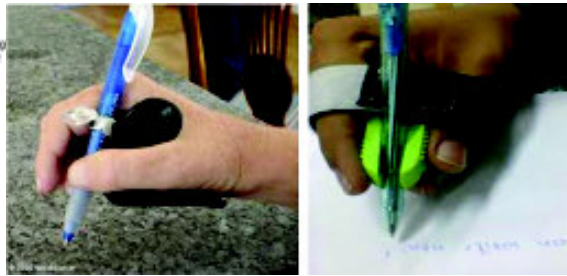


Figure 2



Figure 3



Figure 4



Figure 5



Figure 6



Figure 7

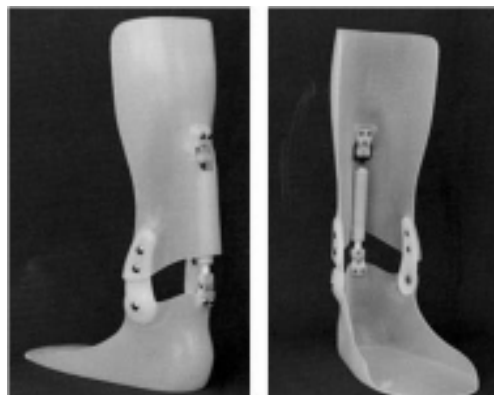
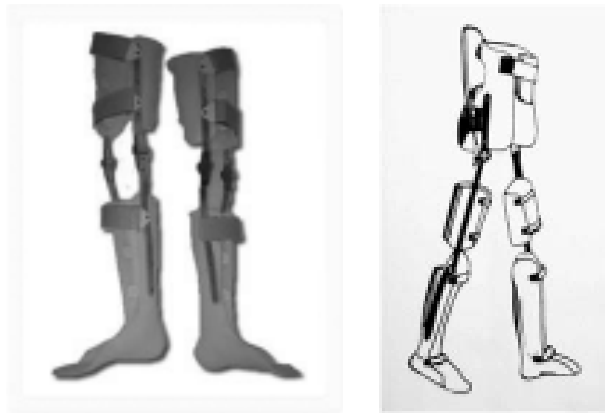


Figure 8



*Figure 9 : Hip Knee Ankle Foot Orthosis*

- Scanner with talking word processor
- Electronic books

### **Learning and Studying**

- Print or picture Schedule
- Low tech aids to find materials ( i.e. index tabs, color coded folders)
- Highlight text ( eg: markers, highlight tape, ruler)
- Software for manipulation of objects or concept development (eg: Blocks in motion, Toy Store). Consider alternate input device (eg: switch or touch window)
- Software for organization of ideas and studying (eg: Inspiration, Claris Works Outline, PowerPoint)
- Recorded material ( books on tape, taped lectures with number coded index)
- Key guard to go over keyboard to help select the right keys and forearm supports to help stabilize upper extremity.

### **Math**

- Abacus or math line
- Calculator, with or without printer
- Talking calculator
- Calculator with large keys or large LCD print out
- On screen calculator
- Software with templates formath computation ( consider adapted input methods)
- Tactile or voice output measuring devices (eg: clock, ruler)

**Recreation and Leisure**

- Adapted toys and games ( eg: toys with adaptive handles)
- Use of battery interrupter and switch to operate a toy
- Adaptive sporting equipment (eg: lighted or bell ball, Velcro mitt)
- Universal cuffs to hold crayons, markers, or paint brush)
- Modified utensils ( eg: rollers, stampers, scissors)
- Ergo Rest to support arm for drawing or painting
- Drawing or graphic program on computer ( Eg: Kid Pix, Blocks in motion)
- Playing games on Computer
- Music software on computer

**Environmental control**

- Light Switch extension
- Use of Powerlink and switch to turn on electrical appliances (eg: radio, fan, blender, and so on)
- Radio and Ultrasound remote controlled appliances

**Vision**

- Eye glasses
- Magnifier
- Large Print Books
- Screen magnifier (mounted over screen)
- Screen color contrast (eg: close view)
- Screen magnification Software (eg: Closeview, Zoom Text)
- Screen reader( eg: Outspoken, Jaws)
- Braille Keyboard and Note taker(eg: Braille N Speak)
- Braille Translation Software

**Hearing**

- Hearing Aid
- Classroom Amplification
- Captioning
- Signaling Device (eg: vibrating pager)
- Screen flash with alert signals on computer

**Environmental Modifications:**

To ensure safe mobility and increase independence of CP child, the physical environment in which he/she functions may need modifications in the form of :

**1) Accessible Entrance/ Exit:**

- adding ramps
- widened doorways
- accessible entrance locks and door handles
- providing an emergency exit
- lightweight doors or automatic door openers

**2) Accessible Interiors:**

- widening hallways or interior doors
- moving electrical switches and outlets
- reinforce wall for grab bars, railings

**3) Accessible Bedroom:**

- widened doorways
- Closet accessibility (lowered shelves, and hanging rods)
- Relocate electrical switches and outlets.

**4) Accessible Bathroom: modify design of**

- commode
- sink and cabinets
- tub or shower
- widened entrance
- moving switches and outlets
- faucet hardware

Other modifications include reinforcing the ceiling if need a lift, roll under sink in kitchen and bathroom, assigning work space in close proximity to school supplies and equipment, modifying workspace or desk design and height

**Splinting:**

Casts, splints, and orthoses are all devices that are designed to maintain the body in a certain position. These devices are used to prevent or correct deformities and/or to help children with cerebral palsy to overcome activity limitations, such as difficulties with standing and walking. An Occupational Therapist evaluates and recommends the use of Upper Extremity, Lower Extremity and Spine splinting to improve, maintain and prevent contractures and deformities.

**Hand Splinting:** Due to difficulty in performing isolated movements of hand, there is affected reach and grasp in children with Cerebral Palsy, hence hand splinting is an important aspect in Cerebral Palsy, for better exploration of the environment and further improving the hand grasp and feeding ability and enhancing the function.

- The thumb in palm deformity is especially frequent and common in children with CP ( Figure 3 ), due to this the thumb is clasped tightly in the palm preventing a normal pinch, grasp and release. An opponens splint or a cortical strap is usually prescribed to bring the thumb out of the palm, allowing for better grasp. This can be used in everyday activities.

Figure 3: Thumb in Palm Deformity seen in CP children

- Static Resting Pan Splinting ( Figure 4 ) : Used to keep the hand in a stretched out position with the thumb abducted and wrist in 20-30 degrees of extension and metacarpophalangeal joints and interphalangeal joints in complete extension.

Figure 4 : Resting Pan Splint

The resting pan splint is usually advised for night splinting and during the the periods of inactivity to stretch the long flexors of the hand to prevent contracture and deformity.

- Functional Cock Up Splint: A functional Cock Up splint ( Figure 5) is used to help keep the wrist and hand in a functional static position, with wrist in 20-30 degree of extension, MP joints in 60-70 degrees of flexion and IP joints in complete extension. Again this splint is used at night and during the period of inactivity to prevent contractures and deformity.

Figure 5 : Functional Cock Up Splint.

- Elbow Guard: An Elbow guard is a static splint given to prevent Elbow flexion contracture and keep the elbow in full extension.
- Static progressive splinting can be done for children with severe contractures and deformity using low density thermoplasts.
- Spinal Braces:

Figure 6: Milwaukee Brace for Scoliosis

For deformities of Spine like Scoliosis (Figure 6), Kyphosis, to position, prevent and correct further Spinal Deformity.

- Lower Extremity Splinting:
  - 1) AFO: Ankle Foot Orthosis (Figure 7)
  - 2) KAFO: Knee Ankle foot Orthosis (Figure 8)
  - 3) HKAFO: Hip Knee Ankle Foot Orthosis (Figure 9)

Figure 7 : Ankle Foot Orthosis

Figure 8: Knee Ankle Foot Orthosis

Figure 9: Hip Knee Ankle Foot Orthosis



- Modified Shoes: for proper weight bearing on the feet and to prevent and correct ankle and feet deformities.

### **Splint Wearing Schedule and Regime:**

Parents and the caregivers should be educated regarding the splint wearing schedule, care of skin and splint and proper techniques of donning and doffing of the splints.

Nonverbal children with poor sensations may not be able to report the sensory problems occurring during wearing of the splint, so a through skin inspection should be taught to the parents and caregivers.

Splint wearing regime should be started initially for few minutes and increased to about 8 hours a day for static splints. Dynamic splints can be worn for more hours according to the tolerance level of the child.

Hand orthosis may inhibit the active use of the extremity. Hence it is important for the child to spend a certain amount of time inbetween the wearing schedule without the splints.

Also regular checkout and modification of splints is required at regular intervals.

## 25. Vocational Rehabilitation in Cerebral Palsy

Vocational rehabilitation is a process which enables persons with functional, psychological, developmental, cognitive and emotional impairments or health conditions to overcome barriers to accessing, maintaining or returning to employment or other useful occupation.<sup>[1]</sup>

Vocational rehabilitation can require input from a range of health care professionals and other non-medical disciplines such as disability employment advisers and career counsellors. Techniques used can include:

- assessment, appraisal, programme evaluation and research.
- goal setting and intervention planning.
- provision of health advice and promotion, in support of returning to work.
- support for self-management of health conditions.
- making adjustments to the medical and psychological impact of a disability.
- case management, referral, and service co-ordination.
- psychosocial interventions.
- career counseling, job analysis, job development, and placement services.
- functional and work capacity evaluations.<sup>[2]</sup>

Vocational training is an education program for adults and a good option for adult with moderate to severe disabilities and help them how to live independently while obtaining job skills<sup>3</sup>. Vocational Rehabilitation is a process to overcome the barriers an individual faces when accessing, remaining or returning to work following injury, illness or impairment. This process includes the procedures in place to support the individual and/or employer or others (for example, family and carers) including help to access VR and to practically manage the delivery of VR; and In addition, VR includes the wide range of intervention to help individuals with a health condition and/or impairment overcome barriers to work and so remain in, return to, or access employment. For example, an assessment of needs , retraining and capacity building , return to work management by awareness, condition management and medical treatment.

British society of rehabilitation Medicine (BSRM) (2003,p.1) describes vocational rehabilitation as a process whereby those disadvantaged by illness or disability can be enabled to access, return to, or remain in , employment, or other useful occupations.

## **EDUCATION IS IMPORTANT**

Education is the cornerstone of our future lives. Education really makes the differences in a child with disability also. It provides door to all our future opportunities. Most everything we are able to do as adults is a result of what we have learned as children. This improves our social standing and increases our ability to be financially and domestically independent and to fulfill our ambitions. The kind of education we receive can empower or inhibit depending on where we are taught, what we are taught, by whom we are taught and with what end in view.

The focus of the education your child receives will impact the skills that he learns, thus deciding what kind of focus his or her education revolves around is quite important, both in the short and long term. If the child's education is aimed at giving him or her the ability to live independently, it is possible that the skills that might lead him to achieving a rewarding career may be cut short, as to make sure he or she will be able to survive independently. If your aim is to help your child by giving him the skills through his or her education to obtain a gainful and rewarding employment opportunity, it is possible that skills that might lead him to live independently will be overlooked to some extent<sup>4</sup>.

Some teens and young adults with cerebral palsy need assistance preparing for independent living. For example, learning to drive a car may require intensive training and a high level of assistance. Occupational therapy used to help with activities of daily living such as dressing, grooming. In adults therapy focuses on vocational training<sup>5</sup>.

Occupational therapists are trained to prepare people with disabilities for these types of events.

Some adults with cerebral palsy live at home until their parents pass away or are no longer able to care for them. These older adults may need the same level of training for independent living that teens and young adults require.

Major independent living skills include preparing meals, handling money properly and using a checkbook, knowing when and where to seek medical care, and driving a car or using public transportation<sup>4</sup>.

## **VOCATIONAL PROGRAMMES AND IMPORTANCE**

Vocational programmes for severely disabled start too late, say around 16 to 18 years of age. In a short period of four years, large number of both general and specific skills will have to be learned. Further, most school-based programmes do not place job placement/employment as a end point of training. Thus, many C.P. young adults graduate from school with no job training or assistance for placement.

This calls for a “Value clarification” of the C.P. school-goer from the parent, educators, the community and the school.

Vocational Rehabilitation ultimately improves the quality of life of the disabled.

***Advantages of employment and vocational training.***

1. Employment in non sheltered integrated setting should be an important objective, for e.g. working with a non disabled person is normal and represent participation in normal work force.
2. Promotes interaction, friendship of the abled with disabled which is really very important in community for acceptance of the disability.
3. Self perception of the disabled working in a normalized integrated setting is higher than the those confined to sheltered or isolated or segregated work environment.
4. The disable performs far better in setting where competent peer models are around to observe.
5. It increases disable’s self confidence, and helps to decrease social stigma.
6. It helps the disabled to perceive his or her self identity and sense of individuality<sup>6</sup>.

Child’s social and cognitive development depends upon the many of the factors like child’s biological health, parent child relationship , acceptance in the family and family education and background. Child’s good social and cognitive ability leads to good schooling and that ultimately contributes to good adult quality of life<sup>7</sup>.(see fig.1)

In cerebral palsied children there is some affectation in child’s social and cognitive development and which ultimately affects school and future development. Vocational training somehow helps the disabled for his or her social development and provides community life and returns enjoyment of life.<sup>8</sup>

- Candle making activity as a vocational activity
- Art and craft activity as a vocational activity
- Jobs identified for persons with Cerebral Palsy<sup>6</sup>
- Computer operator
- Micrographics
- Microphics Clerk
- Mail Order Clerk
- Clerk Typist
- Inventory Information Clerk
- Junior Accounting Clerk
- Remittance Processing Technician
- Mail Rook Clerk

- File Preparation
- Quality Control Clerk
- File Clerk
- Inventory Clerk
- Accounting Clerk
- Data Entry Operator
- Accounts Payable Clerk
- Accounts Receivable Clerk
- Consolidation Account Clerk
- Tape Library Technician
- Switchboard Operator
- Lift Operator<sup>55</sup>
- Document Preparation Clerk
- Key Punch Operator
- Reproduction Clerk
- Xerox Clerk
- Computer Graphics
- Animation
- Horticulture
- Sericulture
- Small /Petty Shopkeeper
- Canteen Management Services, Cashier,
- Supplier
- Sheltered workshop oriented production
- Art Craft Items
- Production of Hand Made Paper items
- Assembling ball pens/switch board
- Bakery items–Production, packing, maintaining of production, cash register
- Production of Tailoring items

### **Vocational Rehabilitation Centers**

There are Vocational training or rehabilitation centers(VRC) available and carries specific objectives for handicapped, following are the objectives and few vocational training centers given.

1. Vocational evaluation and adjustment of the physically handicapped persons.
2. Assessment of the medical, psychological, rehabilitation needs.

3. Assist in developing rehabilitation plans depending upon the specific needs.
4. Sponsor physically handicapped registrants against notified/identified vacancies.
5. Act as distribution centers for various schemes like Scholarship/aids and appliances.
6. Make referrals to financial institution for funding self-employment ventures<sup>7</sup>.

### **Vocational Rehabilitation Centers (VRCs) In India**

1. VRC for Handicapped, ATI Campus, Vidya Nagar, Hyderabad-500007,  
Ph: 040-27427381 Fax: 040-27427381, E-mail: vrchyd@hub.nic.in
2. VRC for Handicapped, Old ITI Campus, Rehbari, Guwahati-781 008.  
Ph: 0361-2607858, E-mail: vrcguwahati@hub.nic.in
3. VRC for Handicapped, A/84, Plot No.1, Gandhi Vihar Police colony,  
Anisabad, Patna-800 002.  
Ph: 0612-2250213 E-mail: vrcpatna@hub.nic.in
4. VRC for Handicapped (Women), After Care Hostel Building,  
Pensionpura, Vadodara - 390 002. Ph: 0265- 2782857  
Fax: 0265-2430510/2430362, E-mail: vrcvadodara@hub.nic.in
5. VRC for Handicapped, ITI Campus, Kuber Nagar, Ahmedabad-382340.  
Ph: 079-22811629. Fax: 22822486 E-mail: vrcahmd@hub.nic.in
6. VRC for Handicapped, Mohalla Baga Mataji, Near Rotary Chowk, Una-174303.  
Ph: 01975-202222
7. VRC for Handicapped, Gogji Bagh, Jawahar Nagar, K.G.Polytechnic Campus,  
Srinagar-190 008. Ph: 0194-2310658
8. VRC for Handicapped, 22, Hosur Road, Bangalore-560 029.  
Ph: 080-26564995 E-mail: vrcblore@hub.nic.in
9. VRC for Handicapped, Nalanchira, M.C. Road, Nalanchira,  
Thiruvananthapuram - 695 015.  
Ph: 0471-2531175, 2530371 E-mail: vrctvm@hub.nic.in
10. VRC for Handicapped, Napier Town, Near Bus Stand Jabalpur-482 001  
Ph: 0761-2405581, Fax. 2390169 E-mail: vrcjabal@hub.nic.in
11. VRC for Handicapped, ATI Campus, V. N. Purav Marg,  
Sion, Mumbai-400 022.  
Ph: 022-24052707, Fax: 25221560 • E-mail: vrcmumbai@hub.nic.in
12. VRC for Handicapped, Plot No.9, 10, 11, Karkar Dooma,  
Vikas Marg, Delhi- 110092. Ph: 011-22372704 E-mail: vrcdelhi@hub.nic.in
13. VRC for Handicapped, SIRD Campus, Unit-8, Bhubaneswar-751012  
Ph: 0674-2560375, Fax: 2560375/2550800, E-mail: vrcbblr@hub.nic.in

14. VRC for Handicapped, Opp. Boat House, Ariyankuppam, Puducherry-605 007.  
Ph: 0413-2602024
15. VRC for Handicapped, ATI Campus, Gill Road, Near Arora Talkies, Ludhiana-141 003.  
Ph: 0161-2490883, Fax: 0161-2491871, E-mail: vrcludhiana@hub.nic.in
16. VRC for Handicapped, 5-A/23, Jawahar Nagar, Jaipur-302004.  
Ph: 0141-2652232, Fax: 2200072, E-mail: vrcjaipur@hub.nic.in
17. VRC for Handicapped, CTI Campus, Guindy, Chennai-600 032.  
Ph: 044-22501534, Fax: 044-22501211 E-mail: vrcchennai@hub.nic.in
18. VRC for Handicapped, Abhoy Nagar, Agartala-799 005.  
Ph: 0381-2325632, E-mail: vrcagartala@hub.nic.in
19. VRC for Handicapped, ATI Campus, Govind Nagar, Kanpur-208022.  
Ph: 0512-2296005, Fax: 0512 - 2296273. E-mail: vrckanpur@hub.nic.in
20. VRC for Handicapped, 38, Badan Roy Lane, Beliaghata, Kolkata-700010.  
Ph: 033- 23508146, Fax: 033-23378358 E-mail: vrckolkata@hub.nic.in
21. DAKSHINYA INSTITUTES FOR THE MENTALLY HANDICAPPED Madhavi Nilayam, J.K.C. College Road, Swarna Bharathi Nagar, Guntur, Andhra Pradesh, INDIA. PIN - 522 006.
22. UMANG 3/4, Kabir Avenue, SFS, Mansarovar, Jaipur, India  
Tel: +91 141 2395099 E-mail: umangjaipur@gmail.com

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2. "Process of VR". Vocational Rehabilitation Association of the UK
3. Vocational Training for People with CP, <https://suite.io/karen-plumley/38z22g6>
4. [http://www.cerebralpalsyworld.com/cp\\_education.aspx](http://www.cerebralpalsyworld.com/cp_education.aspx)
5. Essentials of Physical Medicine and Rehabilitation: Musculoskeletal by Walter R. Frontera, Julie K. Silver, Thomas D. Rizzo
6. <http://www.rehabcouncil.nic.in/writereaddata/cp.pdf>
7. <http://unesdoc.unesco.org/images/0008/000850/085085eo.pdf>
8. [http://www.ilo.org/public//english/region/ampro/cinterfor/tcm/36tcm/doc\\_ref/3/iii.htm](http://www.ilo.org/public//english/region/ampro/cinterfor/tcm/36tcm/doc_ref/3/iii.htm)

## 26. Special Education

Special education helps the child with cerebral palsy to enhance his or her cognitive skills as well as boost the self esteem and sense of accomplishment. The goal is to help the child perform his or her daily activities. The concept of special education for cerebral palsy is to have available devices and supports that allow all individuals to reach a meaningful education that enables them to reach their highest potential. Early intervention begins even before the age of 3 years, working on early childhood programs and extending through secondary education program focussing on mobility, communication and learning.

### **How to Help Students with Cerebral Palsy**

Teaching students with neurological disorders such as cerebral palsy will require a basic understanding of the disability and many classroom accommodations. Having a student with cerebral palsy in the regular classroom has its challenge. When the student has limited mobility, it can require the classroom teacher to make significant changes to the classroom layout and curriculum.

Special education for cerebral palsy patients includes early intervention programs (EIPs) that are family-centered in which professionals and families work together with the child in specific activities. Special educator works on the following areas

- 1) Auditory skills
- 2) Visual skills
- 3) Hand eye co-ordination skills.
- 4) Pre writing and writing skills.

Auditory skills and visual skills can be enhanced by using flash cards and real objects. Working on language helps the child express his or her ideas and understand those expressed by others like sight reading sign language or assistive technology devices (computer, tab etc) to help in communication. Activities for making the child independent and less dependent on parents would be brushing the teeth, indicating toilet needs, asking for water and food. The same can be taught in sign language to non verbal kids.



When a child becomes older and begins formal schooling, the degree of services will vary from individual to individual. Special education for cerebral palsy patients promotes individuals to achieve a substantial degree of independence, however, in some cases some may need considerable assistance. Continuing therapy, regular or special education, counselling, technical support, community integration opportunities, recreation and possible personal attendants may be included in programs aimed at special education for cerebral palsy patients.

Besides special education for cerebral palsy patients, a key factor will always be a supportive factor. People with a severe degree of cerebral palsy can still be functional and independent. Each year the number of students with cerebral palsy attending colleges and universities is growing. The continuation of special education for cerebral palsy patients will expedite these students through higher education and into a world of independent living and accomplishment.

When planning an IEP for cerebral palsy patients there are several qualities in the IEP that need to be addressed. The IEP must first contain a statement of measurable goals. An IEP for cerebral palsy patients should be written with direct connection between the current performance levels and measurable goals over a specific time frame. The goals must be measurable and must specify the expected knowledge, skill, attitude, and behaviour to be achieved within the IEP period.

Parents please don't lose hope. Keep the faith. The most amazing things in life tend to happen, right at the moment you are about to give up hope.

Please refer to these web sites for additional information.

[www.iahp.org](http://www.iahp.org)

[www.nacd.org](http://www.nacd.org)

## 27. Yoga Therapy

Cerebral palsy is an incurable neurological disorder. The management of cerebral palsy is undertaken by a team of multidisciplinary professionals. Therapeutic interventions for CP at present mainly aim to mitigate the deficits and abnormal behaviors associated with Cerebral Palsy, and to increase the quality of life and functional independence of such individuals. Yoga therapy when used in conjunction with other multidisciplinary therapies has shown some improvement in the underlying condition.

Yoga has been used by people all over the world to improve their physical fitness, as a stress reliever, to improve concentrations and lastly to enhance the spiritual experience. But the extrapolation of yoga therapy in the treatment of a myriad of diseases has only surfaced in recent times. In order to truly gain the massive benefits from this ancient science one needs to grasp the complete meaning of Yoga and the manner in which it heals both the mind and the body.

Yoga helps to lower the body's stress response by reducing levels of the hormone cortisol, stimulates the parasympathetic nervous system and improves health by reducing inflammation.

The aim for Yoga therapy in CP is to enhance and develop a greater range of movement while improving coordination and helping to improve the quality of life of patients suffering from CP. Specific Asanas help to stretch and realign the bony structures and facilitate release of tension throughout the muscles in the body.

The deep breathing techniques help in infusing more oxygen into the blood as opposed to regular shallow breathing. This improves in blood circulation and strengthens the weakening muscles and helps in the removal of toxins that accumulate in the body.

We illustrate below some of the simple yet powerful asanas and pranayama that help in these medical conditions

### **Pranayama**

Prana means Life and Ayam means control. Pranayam means control of the inner force of human life. The breath we breathe in and out is regarded as Prana which means bioenergy that endows man with ultimate potential for self-development. It is vital/life force also but man must suitably control and channelize the prana or use it

for right end. Yoga prescribes various practices of Pranayama or control of Prana popularly referred to as breathe control.

### **Pranayama ( I ) : Equalization of inhalation & exhalation (Figure 1)**

#### ***Technique:***

Sit firmly and comfortably. Breath in and out for equal for the equal duration of time.

#### ***Benefits :***

- Augments pleasant feelings throughout whole body.
- Helps to calm the mind.
- Improves air entry in lungs.
- Improved oxygenation of the blood.

### **Pranayam( II ) : Inter costal Breathing**

#### ***Technique :***

Keep both the hands on the side of the chest, make your chest rise up as you breath in for 3 seconds and fall as you breath out for 3 seconds (Figure 2)

#### ***Benefits :***

- Activates the abdominal organs
- Helps in respiration and relaxation.
- Useful in insomnia.
- Facilitates opening of the rib cage and air entry in the lungs.
- Improved oxygenation of the blood.

## **ASANAS**

### ***Sukhansana***

Sukhansana is one of the many asana which quieten the mind. This asana is named for preparedness or conditioning. It is important to achieve the exact posture of this asana but if patients are not able to sit, they can do by lying down. If a child is not co-operative then the parents may need to repeat the asana. (Figure 3)

### **Parvatasana**

#### ***Technique:***

Sit in comfortable pose with both the hands by the side of the body. Raise both hands up while inhaling for 3 seconds. Keep the elbows straight, palms joined together. Hold breath for 3 seconds and then slowly lower your arms with palms facing downwards.



Figure 1



Figure 2



Figure 3

**Benefits:**

- Stretches all the abdominal and pelvic muscles,
- Loosens the hip joints,
- Helps to reduced the flatty and flabby abdomen,
- Improves the shape of body.

**Yastikasana****Technique:**

Lie on your stomach. Fully extend the legs and arms backward. Be relaxed and lift your arms up as you inhale. Maintain this posture for a few seconds and then relax to rest arms and legs. Repeat this pose 3 to 4 times.

***Benefit***

- Corrects faulty posture.
- Tenses the usually relaxed abdominal and pelvic muscles.
- Offers relaxation, when maintaining a non-stretch, passive attitude.
- Removes spasm.

**Eka Padasana*****Technique:***

Stand straight with the feet together and relax the body. Raise the arms above the head and interlock the fingers. Slowly bend forward from the hips, raise the right leg straight back. Keep the trunk, head, leg and arms in a straight line. Focus the gaze on the hands. Hold this final position for some time and then slowly return to the starting position. Repeat the same with the other leg.

In this asana coordinated breathing is essential and should be performed as follows.

***Breathing:***

- Inhale while raising the arms. Exhale while bending to assume the final position.
- Breathe normally in the final position.
- Inhale while returning to the upright position. Exhale while lowering the arms.

***Benefits:***

- This asana strengthens the arms, wrists, hips and leg muscles.
- It relaxes the lower back and helps develop coordination.
- It helps to improve balance

Yoga is an ancient Indian practice for a healthy mind and body. In children with cerebral palsy it may be challenging to achieve the exact postures of the *asanas*, but achieving these postures can improve flexibility and co-ordination of the muscles. *Pranayama* can be practiced in children with cerebral palsy and will be helpful in achieving generalized relaxation of the mind and body, improve air circulation in the lungs thereby enhancing oxygenation of the blood. When practiced along with other rehabilitative therapies it can aid to significantly lower the physical limitations.

## **27. Well Trained Parents are the Best Therapists**

*Contributed by Ms. Maya Nanavati*

### **Well Trained Parents Are the Best Therapists**

Every child is a treasure of hidden potentials- physical, mental and creative. One must know the keys to open that treasure. The right key is the right stimulus of the right intensity at the right time. In normal situation it is very easy to find out about the child's capability by observing his/her reactions towards environment. It is a great pleasure for the parents and the family members to watch their child growing and learning new things, asking questions and exploring the world around. The parents start dreaming about the future goals for their child. All these dreams get shattered for the parents of a cerebral palsy child. First time when they come to know from their doctor that their child has a brain damage and he is suffering from cerebral palsy, they mentally collapse. They feel their life is lost. Initially every parent passes through a phase of denial. Then as their child grows with the problems of physical limitations and resulting into inability to express the mental ability they start accepting the problems. The acceptance of this condition creates a gloomy picture of the future of their child in their eyes. They are haunted all the times with the questions "why me?" "Why my child?" "Why god has punished my child?" The answer to these questions is G.O.K-god only knows. Doctors and the rehab professionals do not have the answers to these questions. But if they believe that the life is an existence of eternal power they can set realistic goals for the cerebral palsy child with positive attitude. They can support the parents and can guide them with simple home program to achieve the set goals. Parents do not need to rush to therapy centre twice in a day daily for months together. Sensible therapeutic program and simple home program repeated many times during the day will lead to far more superior results than intensive therapy at the therapy centre.

The parents need to be counseled that cerebral palsy is a condition due to brain damage and not the disease; therefore, yet no medicine which can cure cerebral palsy. But, one need not be upset about it because whatever is the damage, it has occurred only in 35% of developed brain which is formed at the time of birth.

Remaining 65% develops in first six years of life which we can mold properly if the right stimulus of the right intensity at the right time through therapeutic program. Our brain is plastic and can be molded for desired output with specific stimulus.

The child has to be taken care of in three areas. Physical, emotional and cognitive. The development in all these areas is interdependent. The cerebral palsy child's body is the victim of gravity because of brain damage. His reflexes do not get integrated at the right time. This results into faulty posture and abnormal movement patterns. The brain learns what is fed back. The faulty feedback from the body results into consolidation of faulty network in the brain which aggravates the physical problems further. To break this vicious circle one has to guide the parents to understand the physical problems of their child in relation to gravity. Unwanted gravitational input can be inhibited by simple positioning and also gravitational force can be utilized to facilitate correct motor pattern and reduce spasticity.

The guidelines for the parents are very simple.

- Lying supine for longer time aggravates the effects of TLR and increases the spasticity in upper limbs. It comes in the way of development of protective extensor response resulting into delay in getting sitting balance. Lying supine worsens the condition of the child with opisthotonus by increasing the extensor thrust of the trunk. Therefore, even if the child is asked to wear right splints to keep the lower limbs straight, lying supine should be avoided. (*Figure 1*)
- Child can lie down on the sides with a pillow in-between the legs to avoid gravitational stretch on leg on upper side. The back may be supported by a pillow or a bolter. The opisthotonus child has to be encouraged to sleep in the hammock to nullify the pull of gravity.
- Vojta's horizontal hanging reactions may be used to develop protective extension reaction in the upper limb and to facilitate hip abductors which will automatically reduce adductor spasticity. (*Figure 2*)
- The exercise program needs to be modified considering the child's chronological age. Any child above eight months with poor head control may be given collar and trunk support and may be taught to sit on a chair with cutout tray to send correct feedback of correct posture to the brain. (*Figure 3 & 4*)
- He/she may be encouraged to stand with splints or trunk support to facilitate cerebellar (balancing brain) network. Upright posture is very important for cognitive development. Research reveals that every circuitry in the brain has peak velocity period, if not stimulated optimum the network remains deficit throughout the life. Visual network gets activated automatically once, the child is upright. (*Figure 5 & 6*)
- A cerebral palsy child cannot explore the environment on his/her own because of the physical limitations. It becomes the family members' responsibility to provide the child mental stimuli. Lack of opportunity to learn audio-visually results into pseudomental retardation. Quite a number of these children have



Figure 1



Figure 2



Figure 3



Figure 4



Figure 5



Figure 6

associated hearing or visual problems. They need to be rectified by the concerned experts at the earliest. Cognitive development is the field of occupational therapist. She needs to be very dynamic and creative. While guiding the parents for the activities to achieve gross motor function and fine motor skills she can guide them to teach the child about vegetables, fruits, utensils etc., then asking them to buy pegboards and O.T. games at home. Child's involvement in day to day work increases his self confidence. Once the child's general knowledge



improves, it may be applied for academic learning.

- Guidance from the speech therapist to reduce the child's orofacial sensitivity, facial massage to relax the facial muscles and methods of teaching the child vegetative function is very important. Sucking, sipping, biting, chewing and swallowing are known as vegetative functions. They are the foundation for speech. The parents may be guided to develop breathing control in the child with exercises. Is equally important for speaking properly. Spastic and athetoid children have very shallow breathing and hypotonics and ataxics have poor breathing control. The parents have to be shown the exercise program from day one to improve the child's breathing pattern.

As the child grows up the parents are worried about his/her schooling. If the child is intellectually good he/she may go the regular school. But he school needs to give lot of support. The child may need special chair; special supervision may be multiple choice exam system and then provided with the writer .not all the schools are cooperative. The therapists need to have courage to convince the school authorities to admit the child and provide the child required concessions or modification of exam systems. They need to create awareness about facilities provided by various boards during board exams. Perseverant parents and therapists are successful in getting the child admitted in regular schools. If the child's mental abilities are not up to the mark the parents need to accept that and admit the child in special school. They need to follow the program given by special educators.

Reading this chapter parents may be worried about how to follow so many exercises given by therapists as home program?

Here are few pointers,

One has to look after correct physical positioning throughout the day. If both the parents are working the caregivers need to be trained to look after the child's posture. Once the child is mobile maybe independently, maybe with crutches or walker most of the problems are solved. The parents need to accept the limitations of the child. We have seen that the children accept the external support of crutches and AFO's or walker easily that their parents. These children are like any other children the parents need not be overprotective. From the beginning the child needs to be trained to do all his activities of daily living independently unless the child is very severe and may need the attendant to do his daily routine. But if looked after well from the first year of their life hardly five percent of cerebral palsy children will be there who may need attendant throughout their life

The child has a long way to go. Initial struggle of the parent's perseverance of the child with sensible therapeutic approach by therapists can achieve optimum potential results in every child...

"Sky Is the Limit"

<http://ayjnihh.nic.in/awareness/employment3.asp>

# **SECTION D**

## **Medical and Surgical Management for Major Symptoms**



## 29. Spasticity

### (A) Medical Management

#### **Role of the Neurophysician**

Your doctor will guide you throughout the treatment and place before you the options that available for the management of motor deficits. At the very beginning of the interaction your doctor will confirm the diagnosis by a clinical examination and appropriate tests that would include an MRI of the brain. Once the diagnosis has been confirmed, your child may be started on any of the following medication to alter the tone of the muscles. The options are oral baclofen, oral tolperisone, trihexyphenidyl, tizanidine. These medications are used single or in combination to achieve a good control. Your doctor may suggest a three-month trial with a dopaminergic medicine to improve the quality of movements.

Side effects to the medications may be excessive floppiness, sedation, drooling or excess salivation, vomiting etc and should be reported to your doctor.

#### **Role of orthopaedic surgeon and neurosurgeon**

For children with tight muscles and bony deformities, following options are considered as optimal care for children with cerebral palsy.

#### ***Tendon release surgeries or the newer PMFR techniques:***

Surgical lengthening of the tendons in the leg muscles may allow the child independent ambulation, while similar surgery in the upper limbs may permit improved quality of hand function.

#### ***Botulinum Toxin type A***

This drug is to be injected in the selected muscle to strategically weaken the muscle and then exercise it to strengthen it and at the same time increase the stretch in them to allow a contracture free state.

#### ***Selective dorsal rhizotomy***

This procedure was quite in vogue in the last century and is now offered to very few patients with lower limb spasticity. It involves cutting the nerves after they have been formed in the vertebral column, thereby reducing the spasticity of the muscles by reducing the inhibitory control coming from the brain.

***IntrathecalBaclofen infusion:***

This involves administration of the muscle relaxant internally. The medicine is filled in an infusion pump and is deliver in the spinal canal or the epidural space via a canula thereby releasing a small amount of medicine regularly. This modality of therapy can reduce the total amount of dose used and hence some of the systemic side effects of the oral medication are reduced.

## **(B) BOTOX**

### **What is Botulinum Toxin or Botox?**

Botulinum is a neurotoxin derived from *Clostridium Botulinum* a Gram + anaerobic rod (microbe). It is the same toxin that also causes food poisoning which causes stomach and intestinal problems. Botox is a brand name and not the name of the drug.

### **How does Botulinum work on the spastic muscles?**

Botulinum toxin is an “Exotoxin” i.e., it is secreted / produced outside the cell and on injection in the muscle causes blockage of Acetylcholine release (ACH) at the neuromuscular junction. This Ach causes the muscles to contract. By blocking the release the Ach receptors cannot generate an impulse and thus the spastic muscles undergoes partial paralysis.

### **Are there many types of Botulinum toxin available?**

There are 8 types: A, B, C1, C2, D, E, F and G

Type A is the commonest commercially available botulinum toxin

#### ***Type A:***

- a. OnabotulinumtoxinA : Botox (Allergan Corp- USA)
- b. AbobotulinumtoxinA: Dysport, (Ipsen Corp- UK)
- c. IncobotulinumtoxinA: Xeomin (Merz Pharmaceuticals- Germany)
- d. Neuronox (Medi-tox Korea)
- e. Lanzhou Institute China (No name yet)

### **Which child will benefit with Botox injection?**

Children who have pure spasticity in their muscles without any contracture will gain the maximum benefit. Although, Botox is also used in mixed tone and dystonic children to control some amount of spasticity.

### **How does one administer botox?**

1. Directly inject into the muscle, usually at the area of the largest diameter. May be correlated with the neuromuscular junctions. (1-4 injections/muscle)
2. EMG/Ultrasound guidance.
3. Dose depends on muscle (2-10 U/muscle group). Current dose also based on body weight. 10-15 U/kg doses have been used safely.

One has to choose the target muscles before and decide the total dose required for the child.

The muscles are injected at specific points where the nerve endings are maximum.

This way one can get an optimum response to the drug.

### **How does one assesses the clinical response to the drug?**

Usually, one measures before injection the amount of Spasticity by using the modified Ashworth Score or the Tardieu Scale. The measure of spasticity is recorded.

After injection the response is usually seen in 1 -2 weeks.

### **Do children always need plaster after the injection?**

Children who have severe spasticity may require a cast for 2 weeks. Delayed casting is now advocated as muscle movement is supposed to enhance the efficacy of the drug.

### **Does the child require physiotherapy after Botox?**

Exercise both active and assisted is required to get the maximum benefit after injection. The role of physiotherapy is more important after the injection as one can work on the muscles to improve voluntary control and strength as the spastic muscle is weakened by the injection.

### **How safe is Botox?**

Botulinum injections are very safe provided certain dosage guidelines are adhered to. The technique and site of injection require knowledge and training. In experienced individuals the side effects are minimal which includes mild fever or muscle pain. In children who have respiratory compromise the injection should be used with caution especially in children with quadriplegia.

### **Which muscles are commonly injected?**

Based on the amount of spasticity the common muscles injected are calf for equines deformity or toe walking, hamstring for knee flexor tightness, hip adductors for crossing of leg or scissoring, rectus or quadriceps for knee stiffness in extension and also the strap muscles around the foot to control foot inversion or eversion.

In the upper limb, the injection is used in the biceps tendon, long flexors of the fingers, wrist flexors, thumb adductors to correct various deformities.

Splints or orthosis are very important after the injection as this maintain the correct attitude of the joint for day-day function.

### **Are there any other chemical injections available?**

#### ***Alcohol Blocks (Ethyl alcohol (>10%))***

1. Pharmacology: injected at the motor point and destroys tissue and imparts circulatory damage to denervate
2. Administration: intramuscularly or intraneurally
3. Cost: drug itself is inexpensive, may require anesthesia or sedation for children

4. Side-effects: pain at injection site, chronic dysesthesia, pain, vascular complications
5. Advantages : effects last 2-36 hours
6. Disadvantages: may have side effects, painful

**Phenol Blocks (>3%)**

1. Pharmacology: tissue destruction and circulatory damage
2. Administration: intramuscularly with stimulation of the motor point.
3. Cost: inexpensive, but may require anesthesia
4. Side-effect: pain at infection, chronic dysesthesia and pain, permanent nerves palsy
5. Advantages: long lasting (2-36 months), inexpensive
6. Disadvantages: difficulty locating motor point, side effect, muscle fibrosis

**How long does the effect of botulinum toxin last?**

1. Upper extremities: 4-6 months
2. Lower extremities: 3-4 months

May do serial casting after injection. May be better to wait 1-2 weeks before casting as activity increases the uptake of the toxin

**Any side effects of Botox?**

1. Local Weakness
2. Systemic effects: bowel and bladder control, generalized weakness, dysphasia, dysphagia
3. Effect on local and distant musculature

**What are the advantages of Botox?**

1. Relatively painless
2. Ease of administration (even an orthopedic surgeon can do it)
3. Diffuses readily
4. Transient effects
5. No known cumulative effects

**What are the disadvantages of Botox?**

1. Variable dosing
2. Transient effect
3. Expensive
4. Possibility of antibody formation
5. Long term effect on muscle not known



## (C) Surgical Management

Neurosurgical treatment for spasticity is reserved for severe cases in which medical management has not been effective or has lost its effectiveness. Many times after repeated use of medication the body becomes resistant to these and does not respond to medication any further. In such circumstances neurosurgical intervention may be considered. The most commonly done Neurosurgical procedures for spasticity is Selective Posterior (Dorsal) Rhizotomy (SDR). A more recent procedure that has shown a lot of promise is selective motor Fasciculotomy. Some of the other less commonly done procedures include microsurgical DREZotomy, Peripheral Neurotomy, Longitudinal Myelotomy and Neurectomy. Neuromodulation using Intrathecal Baclofen pump or Cerebellar stimulation are also options in selected cases.

### A. Commonly indicated Neurosurgical procedures:-

#### 1. Selective Dorsal Root Rhizotomy (SDR)

Selective dorsal root rhizotomy aims to reduce spasticity in the legs by reducing the amount of stimulation that reaches leg muscles via nerves. In the procedure, the neurosurgeon locates and selectively severs over-activated nerves controlling leg muscles. This technique can reduce spasticity in some patients, particularly those who have spastic diplegia. Reduced spasticity can improve or create the ability to walk for some children.

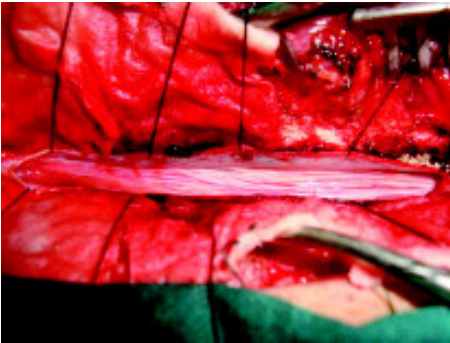


Figure 1: Nerves exposed in the lower back through a laminectomy procedure

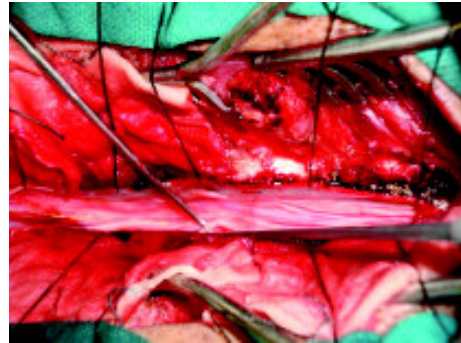


Figure 2: Posterior (Dorsal) roots identified

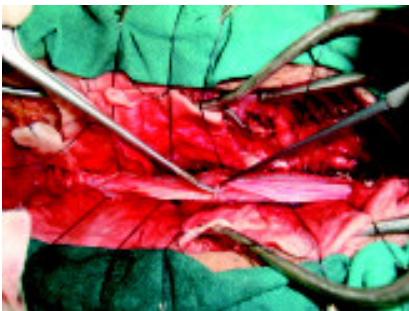


Figure 3: Nerve roots selectively cut

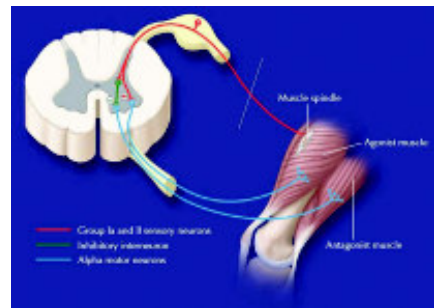


Figure 4: Diagrammatic representation of Dorsal Rhizotomy

The surgery is usually performed when children are between the ages of 2 and 16 years. Because there is so much overlap in the sensory innervations (the supply of nerve fibers) of the legs, there is no loss of sensation when the nerves are cut. The parts of the nerve that are responsible for the spasticity are selected under the microscope by stimulating the individual nerve bundles to check for abnormal responses.

SDR surgery requires exposing four levels of the lumbar spine by lifting up the bones and putting them back (lumbar laminoplasty) to try and avoid spinal deformity. A five to six inch incision is made along the center of the lower back just above the waist in order to expose the nerves and locate the abnormal portions of nerve fiber that need to be cut. An SDR surgery involves sectioning (cutting) of some of the sensory nerve fibers that come from the muscles and enter the spinal cord. Between 50 and 70% of the nerve roots are divided, most surgeons minimize rhizotomy at L4 and S2 to avoid significant quadriceps weakness and bladder dysfunction respectively.

SDR is not done in a few clinical situations including meningitis, congenital hydrocephalus, patients with dystonia, significant athetosis, or ataxia; and those who have very severe scoliosis.

## ***2. Selective motor fasciculotomy***

A new surgical approach of selective motor fasciculotomy of selective nerves has shown promising results in reducing spasticity and preventing its recurrence.

A recent clinical study conducted by Dr. A. K. Purohit and his colleagues tested the efficacy of selective motor fasciculotomy of musculocutaneous nerve to reduce the spasticity of elbow. The procedure was tested in 52 children and total of 75 elbows and in majority of patients the procedure showed complete relief from spasticity and in others it showed reduction in the spasticity. The procedure was safe with no side effects. There was no recurrence of spasticity observed over an average of 17 months of follow up. Another investigative study by Dr. A. K. Purohit and his colleagues selective fasciculotomy of multiple nerves of upper limb was performed in 20 children with severe upper limb spasticity. There was a significant reduction in the spasticity and improved upper extremity functional was noted in all the children, with no side effects of the procedure and no recurrence of spasticity.

## **B. Other less commonly indicated neurosurgical procedures:**

1. **Microsurgical DREZotomy** (Dorsal Root Entry Zone-otomy) is a type of selective rhizotomy. It involves cutting the nerve fibers at the entry zone and suppresses afferent discharges to the spinal cord. It is more effective in the treatment of severe spasticity limited to the upper or lower limbs.

2. **Peripheral neurotomy** involves cutting of peripheral nerves at the point at which they enter the muscle. It is indicated in the treatment of spastic neck, elbow, hand, hip, and foot.

3. **Longitudinal Myelotomy** involves longitudinal division of the spinal cord to sever crossing sensory fibers and produce localized analgesia. It used to be performed earlier for severe and painful spasticity.

4. **Neurectomy** involves the cutting of the nerve branches as they enter the targeted muscle. It is indicated in patients with focal spasticity refractory to botulinum toxin.

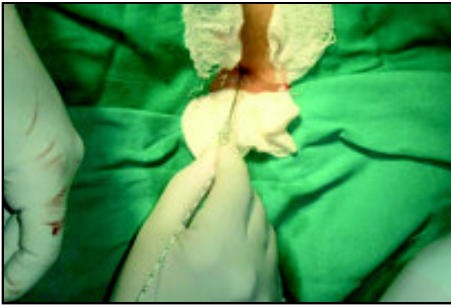
5. **Stereotactic Thalamotomy** is a form of functional Stereotactic Neurosurgery which is a three dimensional minimally invasive technique of Neurosurgery. It consists of using an MRI to map a structure within the Brain. Once this is done, the coordinates are moved to a stereotactic frame, which will guide an electrode to the exact location. Most of the time, the procedure is done under local anesthesia, depending on the conditions of the patient. The stereotactic frame is fixed in the skull and the electrode is driven through a burr hole. While small electrical discharges are applied intermittently, the surgeon watches the response of the patient and in this way, knows the exact position of the electrode within the brain. Once in the target, a larger electrical impulse is sent through the electrode to modify the brain cells at that spot. Stereotactic Thalamotomy involves operating in a specific area of the brain, the thalamus, which is the brain's relay station for messages from the muscles and sensory organs. This procedure has been shown effective only for reducing hemiparetic tremors

### C. NeuroModulation :

Neuromodulation is a therapeutic alteration of activity either through stimulation or medication, both of which are introduced by implanted devices.

#### 1. *Intrathecal Baclofen pump:*

The poor penetration of blood-brain barrier and significant side effects of oral Baclofen can be minimized by intrathecal administration (directly into CSF) via a programmable pump. Considerably lower doses are required in intrathecal injection and it is without the development of tolerance. It should be considered in patients unresponsive to oral pharmacotherapy and a severity of 3 on the Ashworth scale for at least 12 months. A test dose should first be given intrathecally before the pump is implanted. The dose range is 12 - 2000 mcg/d and should be fine tuned according to the severity of symptoms and response to therapy. The complications of intrathecal Baclofen pump implantation are relatively few and usually are limited to mechanical failures of the pump or the catheter. Adverse drug effects are usually temporary and can be managed by reducing the rate of infusion. The problem in our country for the use of intrathecal Baclofen pump is the expense of the pump so it is not done very frequently. 0



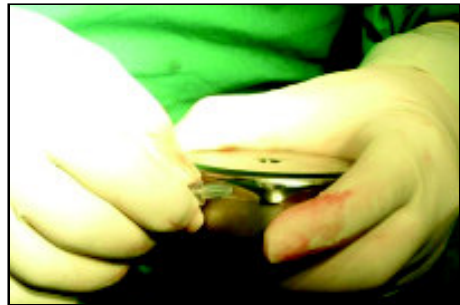
*Figure 5: A lumbar puncture is done in the lower back and a catheter is inserted*



*Figure 6: The Baclofen pump is filled with liquid Baclofen*



*Figure 7: A connector is introduced between the back and the front of the lower abdomen*



*Figure 8: The catheter from the lumbar puncture is connected to the Baclofen pump*



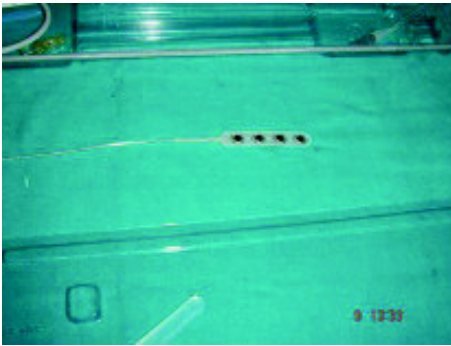
*Figure 9: The Baclofen pump is placed below the skin in the front of the abdomen*



*Figure 10: The dosage of the Baclofen can be managed from an external controller*

## *2. Chronic Cerebellar Stimulation:*

In chronic cerebellar stimulation, electrodes are implanted on the surface of the cerebellum — the part of the brain responsible for coordinating movement — and are used to stimulate certain cerebellar nerves. While it was hoped that this technique would decrease spasticity and improve motor function, the results of this invasive procedure have been mixed.



*Figure 11: Electrodes that are placed on the cerebellum*



*Figure 12: Neurostimulator that is connected to the electrodes and implanted in the upper chest wall below the skin*

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## 30. Epilepsy

The management of epilepsy includes acute management during an actual seizure and long term management as discussed below.

During an active seizure; following suggestions are to be exercised

- Stay calm. Unfortunately, once a seizure has started, it cannot and should not be stopped.
- Know what to expect. Being aware allows you to alter the environment so the child isn't physically harmed during the seizure, for example, falling and/or hitting his head on a hard surface
- Place the child in a recovery position, i.e. on his side. If the child vomits, this will prevent aspiration
- Place the child on a protective surface
- If the child is an infant, lay him or her down
- Support the child's head with a soft object
- Make sure the child is breathing
- Loosen tight-fitting clothing

Importantly following things should never be done during a seizure

- Don't put objects such as a tongue depressor or spoon or your fingers in a child's mouth
- Don't restrain the child from physical movement
- Don't allow the child to handle objects
- Don't give the child food or liquids
- Do not smell him anything like chappals or shoes
- Do not place metals in their hands

Long term management of children with epilepsy

- A) Medical Management
- B) Ketogenic Diet
- C) Surgery for Epilepsy

### ***Medical Management***

Your doctor can decide the best medicine for your child. There are different medications for different type of seizures. The choice of the medicine shall depend upon the age of the patient and the type of seizure. The dose of each medicine varies and do not compare the absolute amount of each medication. Your doctor is the best judge and shall prescribe it at an appropriate dose.

Please ensure that you administer the dose of medicine in the right amount and at the scheduled time. Please check with the doctor regarding the possible side effects of the medication and observe for the same in your child. Please notify your doctor immediately on noting the side effects of the medication. Kindly note that each individual shall respond differently to a given medication and hence do not compare with a medication that your relative or friend is using and never use any medication without a proper prescription.

Sodium Valproate, Lamotrigine, Levetiracetam, Topiramate, Steroids, Clobazam, Clonazepam, Lacosamide, Phenytoin, Phenobarbitone etc are some of the medications that your doctor may prescribe for your child. As a thumb rule 65-75% of children will respond to medication, but the response rate to medications may be lower in children with cerebral palsy. At times your doctor may prescribe more than one medication for better control of the seizures. The medical literature supports polytherapy, however when the number of medications increases beyond three, there is no added benefit to be achieved and at times your doctor may advice a minimalistic attitude to reduce the number of medications to achieve a reasonable seizure control but with improved quality of life. In children with refractory epilepsy this may attain importance over the seizure freedom.

### ***Ketogenic diet***

In children with refractory epilepsy, after the medical management has failed, your doctor may advice you to opt for ketogenic diet. This dietary therapy is rich in fats and low in carbohydrates and proteins. The high fat content in the diet brings about metabolic changes in your body that help you to achieve seizure control. This diet regime is to be followed under the guidance of a neurologist and a trained dietician. To know more about the diet you could speak to your neurologist or pediatrician.

### ***Surgery for Epilepsy***

For patient with epilepsy this is a new modality of therapy where after a detailed evaluation the focus of seizure onset is clearly identified and then removed by a surgical procedure. For children with cerebral palsy this may not be a very successful or feasible option, but should be duly considered if a child is indeed deemed suitable for surgery. Your neurologist can advice you further after studying the patients MRI scans, EEG and the clinical profile.



## 31. Physical impairments and deformities in Cerebral Palsy

### When is orthopedic surgery carried out in these children?

Orthopedic surgery is typically carried out after age 5 - 6 years. Surgery prior to this age has been associated with weakness of muscles, recurrence of deformity and poor results in adolescents. Indiscriminate cutting of tight tendons as practiced earlier still continues in some centers leading to gross deformities as these children grow and gain weight.

Certain principles and guidelines over the years have made surgery safer and more predictable. The adage “decision making is more important than making incision” holds true here. Every child undergoes a thorough assessment of his tone disturbance, muscle tightness, joint position and function. Special x-rays may be required before the surgery. The surgical plan is discussed with the concerned therapist so that the post-operative physical therapy is planned at the appropriate time.

### What are the common procedures done for release of contractures?

Common Orthopaedic Procedures include fractional lengthening or myofascial release, tendon lengthening with “Z” procedure, tendon transfers, and bone surgery (osteotomy) and joint fusion (arthrodesis).

Muscle release is carried out either open or with minimal skin incision.

Once a treatment plan is made for a particular child, then all muscles releases are performed at one time popularly known a “Single Event Multi-Level Surgery” of SEMLS. This concept has gained significance due to better anesthesia for these children, good pain control and better understanding of the pathology of CP. In the past many children would undergo surgery every



*Figure 1 Thorough assessment to prevent over correction*



year (Birthday Syndrome) at different muscle levels causing great hardship for the parents and child.

### **What surgery is done for hip contracture?**

Orthopedic surgery is carried out around the hip to decrease crossing of scissoring of the legs (adductor release). This helps the child to spread his legs and improve standing balance and even hygiene in the perineal area. Children who are non-walkers or with poor balance and scissoring posture of the legs are at risk of hip dislocation and will greatly benefit from hip release to prevent complete displacement of the joint.

Children who bend forward and lean while walking have weak hip extensors. These children can use a posterior walker to stand erect and if the anterior hip muscles (flexors) are tight then a soft tissue release will be required.

### **What type of surgery is done for knee contracture?**

Knee bending of Flexion also prevents locking of knee and interferes in walking. In mild cases a posterior knee splint will prevent worsening of contracture. In child with severe tightness or those who cannot tolerate the splint then a posterior knee release (Hamstring Tendon) will be required.

### **Is foot surgery required in these children?**

Foot surgery is required in children when the foot shape or attitude of foot joints causes skin problems or callosities indicative of abnormal pressure. Any type of foot shape can be accommodated in an orthosis or splint and if the child is comfortable and the standing or walking is not affected then surgery can be deferred as late as possible. Tendon



*Figure 2. Pre and Post Single Event Multi-Level Surgery*



*Figure 3. Pre Hip Dislocation*



*Figure 4. Pre and Post Correction of Knee Deformities*

release or transfers may be required in children older than six years to balance the foot.

### **Are older children different from small children regarding treatment of muscle contracture?**

Older children with Cerebral Palsy (more than 12 years) present a unique problem. These children may present due to worsening of leg deformity as the height and weight has increased. These children require bony surgery as any soft tissue release tends to make them weaker. A thorough assessment is required, along with joint consultation with the therapist, as following surgery, these children require extensive rehabilitation.

### **Are there any preventive strategies for upper limb in CP?**

Upper limb involvement is also very common in cerebral palsy. Many times the fingers are twisted into abnormal posture, the wrist is bent down and child had difficulty in holding objects. Again, here the preventive approach is to use active stimulation and splints to control movements. Botulinum injection is very useful to treat and also predict if any tendon transfer and osteotomy would be useful. Many children can achieve gross function.

### **What do you mean by integrated care for cerebral Palsy?**

Thus many children with cerebral palsy will benefit with an integrated approach in a Child Development Center (CDC) where they are assessed by a team of doctors including physiotherapist, occupational therapist, orthopaedic surgeon, neurologist and special educators. Pre-emptive or precautionary steps like splints or orthosis, casting with or without Botulinum Injection, can help lead the child a more functional life. Surgery should be deferred as late as possible to preserve joint shape, function and range of motion.



## **SECTION E:**

### **Recent Advances**

## 32. Stem Cell Therapy in Cerebral Palsy

There is a new revolution in the medical world. A revolution that has taken the scientific world by storm. A revolution, which was awarded the 2012 Nobel Prize in Medicine. A revolution that is redefining the words incurable and untreatable. A revolution that is reshaping the way we now think about neurological disorders. A revolution that will forever make a huge difference in the lives of children with cerebral palsy. This revolution is called **“Stem Cell Therapy”**. It is not often that quantum leaps occur in our understanding and treatments of various medical conditions but stem cell therapy is definitely one of those leaps. Rapidly developing advances in this field are forcing medical practitioners and scientists to completely rethink everything that was believed about various so called “incurable” conditions specially those involving brain and spine. However, whilst there is lot of hope about stem cell therapy, there is also a lot of hype and it is important to make a distinction between these two. Also there are a lot of misconceptions about what stem cells are, the ethics of its use, the safety of the treatment and the effectiveness in various conditions/disorders. The above issues have been discussed scientifically by us in a chapter- **“Stem Cell Therapy for Cerebral Palsy- A Novel Option”** of an international book **“Cerebral Palsy- Challenges for the Future”**. For better understanding of parents, here, we have attempted to clarify these aspects of stem cell therapy in a simplified manner. We shall initially discuss the basic facts about stem cells and how stem cell therapy is done. We will also present our own experiences and clinical results in simplified way. Almost all of the available scientific references have been listed at the end of the chapter, so that parents can source the original writing and get a complete perspective. This chapter concludes with a discussion on the dilemmas and debates around stem cell therapy. The purpose of this chapter is to put forth all the facts about stem cell therapy, thereby helping parents make an informed choice about whether they would want to opt for this treatment for their children.

### **Rationale for using Stem cell therapy for Cerebral palsy**

Routine neuroimaging, such as MRI brain and more recent advances in modern

imaging using PET CT Scan of the brain brings out the heterogenous nature of the damage in a CP child's brain. This may range from PVL (periventricular leucomalacia) consisting of damage to the deep white matter. This affects the developing connections of the various regions of the brain, viz. oligodendrocytes and other supporting tissue. The other extreme can be cystic vacuolation of the brain, viz. damage to the grey matter or neurons of the brain. This leads to various disabilities and neurodeficit, which has been discussed in a lot of details in the previous chapters.

Whereas, rehabilitation methods, certain medications and targeted surgeries, help in alleviating some symptoms of cerebral palsy, they do not correct the root problem within the brain. Stem cell therapy by virtue of their actions of producing positive chemicals within the brain such as nerve growth factors, increasing the blood supply to these damaged areas and by converting into brain cells, initiate a process of repair and regeneration which addresses the very core of the problem. Stem cell therapy, therefore, has the potential to produce much better clinical improvements, as compared to earlier methods. There is now enough evidence, in the form of published scientific papers in international journals /books highlighting the safety and beneficial effects of stem cell therapy in children with cerebral palsy (*references listed at the end of the article*).

As a treatment form, it is an extremely simple treatment, which involves the child getting only 2 injections (there is no major surgery involved) and has not been associated with any significant irreversible neurological complications.

### **What are stem cells?**

Stem cells are specialized cells, which can multiply manifold, can convert to any type of tissue of our body & have the ability to reach and repair damaged parts of the body.

### **What are the types of stem cells?**

There are many types of stem cells, but broadly they can be classified into 3 types:

a) Embryonic stem cells, b) Umbilical cord stem cells, c) Adult stem cells

Embryonic stem cells are derived from the embryo or an unborn foetus. However, there are many ethical and medical issues regarding its use. These are therefore not being used commonly at present. Umbilical cord stem cells are derived from the umbilical cord which connects the baby and mother at birth. Stem cells derived from the umbilical cord are stored by various cord blood banking companies. These stem cells do not have any major ethical issues surrounding their usage, however, availability can be an issue in different places. Adult stem cells can be derived from the same patient, from either the hip bone or the fat/adipose tissue. These are the safest and most popularly used stem cells at present and availability is not a problem.

The advantages of adult stem cells are that, since they are derived from the patients themselves, there are no major side effects or complications associated with their

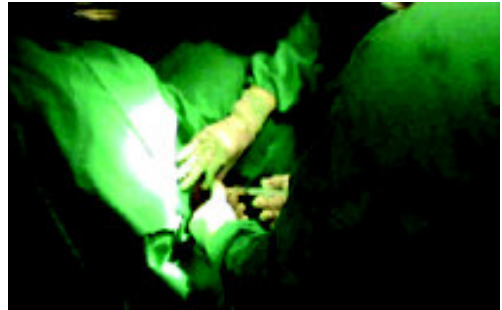
use. There are also no ethical issues with regards to these. We use adult stem cells only and all further information in this chapter is based on adult stem cell therapy.

## How is stem cell therapy done? (at the NeuroGen Brain and Spine Institute )

*This is done in 3 simple steps.*

*Step1: **Bone marrow aspiration:** (done in the operation theatre)*

This is done by putting a needle into the hip bone, after making the the area numb with a local anesthetic, so that the child does not experience pain. 80-100 ml bone marrow is aspirated from the inside the bone. This takes about 20 minutes.



*Figure 1: Bone marrow aspiration*

*Step 2: **Stem cell separation:** (done in the stem cell laboratory)*

The bone marrow removed from the child is taken to the stem cell laboratory, where the stem cells are separated from the remaining cells of the bone marrow. This takes about 3 hours.

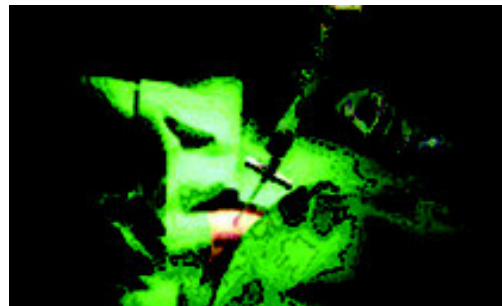


*Figure 2: Stem cell separation*

*Step 3: **Stem cell injection:** (done in the operation theatre)*

A very thin needle is inserted into the lower back of the child, after making the area numb with a local anesthetic and the stem cells are injected into the fluid surrounding the spinal cord and brain (CSF). Around 50 million cells are injected this way. This takes about 20 minutes.

All the above are completed on the same day.



*Figure 3: Stem cell Injection*

## Neurorehabilitation after stem cell therapy

Following the stem cell transplantation or injection, from the very next day, patient undergoes an intensive rehabilitation process, consisting of physiotherapy, occupational therapy, speech therapy, psychological therapy, positive reinforcement processes, yoga therapy, specialized diets etc. It is important that stem cell therapy

be followed by a proper rehabilitation regime to gain proper response. Stem cells are considered to be “blank slates”, which means they are programmable.

At NeuroGen BSI, our experience has reaffirmed that the cells can be programmed and guided to help regenerate tissues by doing appropriate rehabilitation. We believe that the stem cell therapy works along with an extended and aggressive Neurorehabilitation process. In fact we call our entire treatment of stem cell therapy and Neurorehabilitation as Neuro-Regenerative-Rehabilitation Therapy (NRRT). Our long term follow-up reveals that patients who participate in a regular rehabilitation program do overall better than those that don't. The availability of the transplanted stem cells make the rehabilitation process more effective and efficient.

### Clinical results of Stem Cell Therapy:

At Neurogen BSI, we have treated over 150 CP cases. In an analysis of 108 patients with maximum follow up of 4 years, stem cell therapy was found to be safe and effective in 92.6% of the patients. Improvements were in seen in symptoms like oromotor/speech, balance, trunk activity, upper limb activity, lower limb activity, muscle tone, ambulation and activities of Daily Living .

Out of the 108 patients, 15.74% showed significant improvements, 48.14% of patients showed moderate improvements and 28.7 % showed mild improvements.

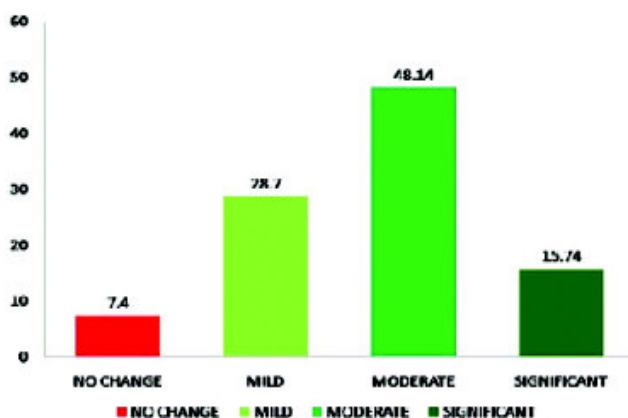


Figure 4: Graph showing improvements in CP after stem cell therapy

### Progressive improvements seen after stem cell therapy:

After stem cell therapy, immediate improvements were observed within a week in muscle tone, involuntary movements of the limbs, head control and drooling.

From 1 week to 3 months of intervention, improvement in voluntary control resulted in initiation of opening and closing of fingers and improved midline orientation. As the tone of the hypertonic muscles reduced, trunk control, sitting balance and gross motor movements of limbs also improved.. Many patients also showed improved oromotor activities.



From 3 months to 6 months of intervention, eye hand coordination was better due to improved head control and gross motor skills. Sitting balance improved further along with initiation of weight shifting while sitting. Maintaining upright position, dynamic trunk balance and weight bearing on legs improved. Initiation of steps while walking with support and/or assistive devices was also seen in patients who were not able to walk previously. Muscle tone and motor control and independence for daily activities improved.

Cognitive skills and understanding improved progressively from one week to six months. Cooperation during therapy sessions was better due to which it was easier for the caregiver to handle the patient. Cognition improved with respect to awareness, understanding, response time and command following.

Some patients were followed up even after six months, 1 year, 2 years, 4 years. These patients showed improvement in fine motor activities. Equilibrium reactions developed along with increase in dynamic balance. Speech started improving in the aspects of clarity, fluency and intelligibility. Individuals with monosyllable speech developed bisyllable speech, bisyllable improved to word formation and words improved to phrases. There was also gradual improvement in ambulatory status.

### Objective improvements on PET CT Scan Brain:

PET-CT scan was done to monitor improvements in the metabolic activity of the brain. The PET scan measures the 18-FDG uptake which correlates to the glucose metabolism in the brain. The damaged areas of the brain in CP are functioning low and any improvement in the functioning of these areas will lead to an increase in the FDG uptake. Previous studies in patients with CP have shown reduced metabolic activity in various areas of the brain depending on the individual case. A comparative scan performed before and after cell therapy demonstrated increased metabolic activity in frontal, parietal, temporal, basal ganglia, thalamus and cerebellar areas of the brain. The clinical and functional improvements correlated to the changes observed in the PET scan. Improved metabolism in frontal and temporal areas led to

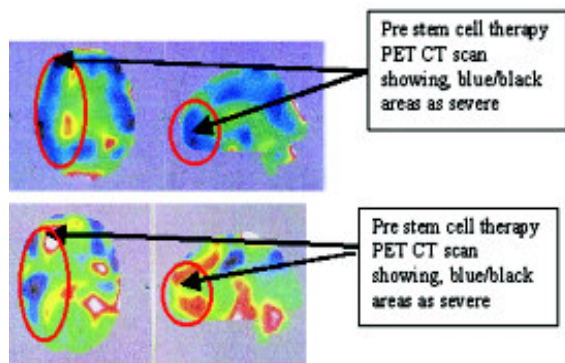


Figure 5: Pre and Post Stem Cell Therapy Comparison of PET CT scans.

improvement in speech and memory. Improvement in basal ganglia led to improved voluntary movement and coordination. Improvement in parietal area led to improved awareness and improvement in cerebellum led to improved balance and fine motor coordination.

Various studies from all over the world (India, China, Russia, etc) using different types of stem cells viz. bone marrow derived cells, umbilical cord blood cells, neural cells, olfactory ensheathing cells have also reported safety and efficacy of these cells in cerebral palsy children. They have been found to improve motor and functional improvements over a period of six months.

### **Adverse Events / Complications**

None of the children had neurological worsening or clinical deterioration. There are some minor post procedure effects, such as headache or nausea, which occur in some patients but which settles in 2-3 days. This is part of the procedure of injecting into the spinal fluid. It is called a spinal headache.

Epilepsy is the only significant adverse event that can occur. However, we have noticed that it does not occur in patients who are already on anticonvulsant medications and also does not occur in those children who have a normal EEG before the treatment. Although, in those children whose EEG shows abnormal epileptic activity and who are not on anti epileptic medications seizures can occur.

To prevent this it is recommended that an EEG be done before the stem cell therapy. If it is normal then there is nothing to worry about. If it is abnormal then it is recommended that antiepileptic medications be started before the stem cell therapy and be continued for a 6 month period. Those already on antiepileptic drugs should continue these as before and after the stem cell therapy. With this strategy the possibility of seizures or an increase in seizures is reduced.

### **More about pathophysiology (what happens in cerebral palsy) of cerebral palsy and stem cells:**

During childhood, the brain is at its maximum growth phase, hence cellular therapy or stem cell therapy at this stage becomes a potent modality in children with cerebral palsy. Various experimental studies have demonstrated that cell transplantation in the CP models lead to survival, homing and differentiation of cells into neurons, oligodendrocytes and astrocytes (support cells).

Stem cells stimulate the repair process by homing to the injured sites of the brain and carrying out regeneration. Injury to the brain at and around the time of birth, leads to the damage of the stem cells in the brain. This leads to loss of the inherent regenerative potential of the brain. Stem cell therapy, hence, restores the lost cells and helps form newer cells and connecting cells. It may also support their survival by introducing other cell types able to restore missing enzymes to an otherwise deficient environment. Stem cells also reduce the levels of harmful chemicals, such as, TNF- $\alpha$ , IL-1 $\beta$ , IL-1 $\alpha$ , IL-6 raised due to activation of cells forming a scar tissue in the brain, enhancing the endogenous brain repair. These cells also secrete neurotrophic factors and growth factors such as connective tissue growth factor, fibroblast growth factor 2 and 7, interleukins, vascular endothelial growth factor (VEGF), fibroblast growth factor (FGF), and basic fibroblast growth factor (bFGF)

which are responsible for cell multiplication, protection of brain cells and angiogenesis/formation of new blood vessels, retrieving the lost tissue functions.

### **How do stem cells work?**

Following stem cell therapy, a patient first experiences an overall feeling of well being .This is attributed to the release of “good chemical signals”, referred to as cytokines and factors known as “Nerve growth factors” and “Brain derived neurotrophic factors”. Over a period of time, the process of “Angiogenesis” or formation of new blood vessels is initiated over a few weeks and months. Over 2-3 months, Neurogenesis or formation of neural cells also happens.

### **Why bone marrow derived cells? Why are they injected into the spinal fluid?**

Studies have demonstrated that whole bone marrow mononuclear cells are a mixture of hematopoietic stem cells, mesenchymal stem cells, endothelial progenitor cells, macrophage, and lymphocytes. Together they exert a better effect compared to the individual fractions of the cells.

These cells are injected intrathecally as it is minimally invasive, safe and an effective route of administration. Intracranial (direct injection into the brain) transplantation may be more targeted but it involves risk of increasing the damage. Intravenous administration being the simplest, leads to the majority of cells being trapped in organs other than brain such as lung, spleen, kidney and intestine.

### **Conclusion**

Intrathecal autologous stem cell therapy is safe, feasible and effective treatment strategy for children with cerebral palsy. This repairs the underlying brain damage which can also be objectively seen on PET CT scan of brain along with improvement in functional and achievement of milestones in children. Stem cell therapy along with standard treatment augments the development and improves the quality of life of these children.

## A special discussion

### The Dilemma, The Debate, Suggestions

#### *The Dilemma*

A major dilemma being faced nowadays by parents and patients of Cerebral palsy is as to whether they should consider Stem Cell therapy as a treatment option. On one hand they are flooded with information on stem cells through the press, media, internet, etc and on the other hand they are told by their primary doctors that this treatment is still unproven or that it does not work etc. These diametrically opposite views create a lot of confusion and conflict in the minds of the patients and their families.

In this chapter, we have given some basic information on what stem cells are and how it is done and we have shared some of the clinical results obtained with this therapy.

The fundamental questions that arise in the minds of parents and patients are:

- Does Stem cell therapy really work for cerebral palsy?
- Are there any dangers or risks of doing this therapy?
- What improvements are likely to be seen in the patients with this therapy?
- How do I choose a good center for stem cell therapy and how do I know for sure whether the center I have chosen for stem cell therapy is working to high professional, medical, scientific and ethical standards ?

#### *The Debate*

There are two sides to this debate and we shall address both.

- **Point of view - 1 - For (reasonable view):** That Stem cell therapy is safe and works in cerebral palsy in terms of functional improvements and helping to develop his/her milestones.
- **Point of View - 2 - Against (reasonable view):** That Stem cell therapy is not a proven treatment and we are not sure that it works. Even if it works, the effects regress or it may also lead to regression in the child's development.

In an extreme form these two above points of view sometimes get expressed as:

- **Point of View 1- For (extreme view):** Stem cell therapy is a definitive cure for Cerebral palsy
- **Point of view 2 - Against (extreme view):** Stem cell therapy is a dangerous, banned

#### **Is Stem cell therapy safe?**

To understand this we must first realize that stem cells are not one single entity. This has been discussed earlier in this chapter.

There are broadly speaking three different types of stem cells. These are embryonic stem cells, umbilical cord derived stem cells and adult stem cells. Whereas, it is true that embryonic stem cells are potentially dangerous (due to the possibility of their forming tumors called teratomas) and have various ethical issues associated with them, umbilical cord and adult stem cells are not dangerous in any way (there is no risk of tumor formation with them) and are not associated with any major ethical issues. It is the lack of understanding the fact that there are different types of stem cells and that the risks associated with one are not applicable to the other is what creates a lot of confusion.

There are several scientific publications to show that umbilical cord and adult stem cells are safe. In fact a review of all the publications based on these show that there are virtually no major adverse events reported that are connected to these types of stem cells. Based on all the scientific literature and our own clinical experience we can say with a reasonable surety that adult stem cell therapy is safe and without any major or significant risk factors.

### **Is Stem cell therapy effective for cerebral palsy?**

Regarding the effectiveness of stem cell therapy in cerebral palsy, we have already discussed about our experience in over 100 patients with cerebral palsy.

We have used bone marrow derived autologous adult stem cells which were injected intrathecally. Earlier in this chapter, some details of these results are given of 108 patients. Broadly, Stem cell therapy was found to be safe and effective in 92.6% of the patients. Improvements were seen in symptoms like oromotor/speech, balance, trunk activity, upper limb activity, lower limb activity, muscle tone, ambulation and Activities of Daily Living.

Also from an ethical point of view there is a basis for offering this form of therapy.

### **As per World Medical Associations Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Subjects:**

*"In the treatment of a patient, where proven interventions do not exist or have been ineffective, the physician, after seeking expert advice, with informed consent from the patient or a legally authorized representative, may use an unproven intervention if in the physician's judgment it offers hope of saving life, re-establishing health or alleviating suffering. Where possible, this intervention should be made the object of research, designed to evaluate its safety and efficacy. In all cases, new information should be recorded and, where appropriate, made publicly available."*

Cerebral Palsy definitely fits into this definition since "proven interventions" do not exist or have been ineffective.

Therefore from an ethical point of view, as per the Helsinki declaration, for children with cerebral palsy, it is appropriate to use stem cell therapy as a medical intervention.

With our own clinical experience of over 100 patients of cerebral palsy treated with Stem cells we can say that it definitely helps in "re-establishing health or alleviating suffering". So despite the fact that as per the principles of evidence based medicine,

stem cell therapy is still an unproven treatment but on the basis of the Helsinki declaration it may be used since there are no other proven interventions. If, instead of looking at this through the lenses of evidence based medicine, we look at this from the lens of practice based medicine then we cannot say that it is an unproven therapy since there is enough clinical evidence to show that stem cell therapy definitely helps.

### Counterview

One swan does not make a summer. Just because at one or a few centers there are good results does not make it a standard of care. It will take many more centers to show the same results (preferably with a comparison with controls) before we can accept it as a standard of care.

Now let us look at the other point of view which is:

- **Reasonable point of View 2 (Against Stem Cell therapy):** That Stem cell therapy is not a proven treatment and we are not sure that it works.

For the above:

There is substance to this point of view. Today the practice of Modern medicine is based on what is called “evidence based medicine”. For a treatment to become a standard of care it should have been evaluated by multiple centers through what are called prospective, randomized, double blind, placebo controlled studies. This type of evidence is called Level I evidence. At present, we do not have Level I evidence for the role of stem cell therapy in cerebral palsy. So when your doctor says that this is not yet a proven treatment then based on the principles of evidence based medicine that statement has a basis. By these standards it is also not incorrect for any doctor to say that “we are not sure that it works”.

**Counter argument:** It will take several years (anywhere between 3-7 years) before class one evidence in the form as mentioned above is generated. But till then, these children are growing and have been kept bereft of timely intervention, which has the potential to help them become independent.

Regarding the two extreme views that:

- Stem cell therapy is a definitive cure for cerebral palsy
- Stem cell therapy is a dangerous, banned and unethical form of treatment we wish to state that neither is true.

Stem cell therapy does not cure cerebral palsy. That view or statement is completely incorrect. What it does is that it reduces spasticity, improves milestone development, voluntary movements/activity of hands and legs, improves oromotor activity (swallowing & speech), cognition, balance, reduces dystonia and involuntary movements.

The other extreme view is also incorrect. Stem cell therapy (especially with adult stem cells and umbilical cord stem cells) is not dangerous in any way whatsoever. It

is also not banned treatment. The confusion of its being banned comes from the fact that in the year 2001, President George Bush of America imposed a ban of the federal governmental funding of embryonic stem cell research. It should be noted that:

- Ban was only for the federal (government) funding of research
- Ban was for embryonic stem cells only and not for adult stem cells and
- That even this ban on the “federal funding for embryonic stem cell research” has subsequently been lifted by President Obama as soon as he became President in the year 2008. Different countries have different regulations and guidelines for use of stem cells. In the US the body to approve this is the US FDA. In India, the regulatory body for Stem Cell research is the Indian Council of Medical Research. According to its guidelines it has put embryonic stem cells in the restrictive category but adult stem cells and umbilical cord cells are in the permissive category. It is also not unethical to treat individuals with cerebral palsy with adult stem cells since it falls under the category of diseases for which there is no proven intervention and so as per the Helsinki Declaration an unproven therapy can ethically be used. So in summary whilst Stem cell therapy is not a definitive cure for cerebral palsy, it does produce clinical improvements but it is neither a dangerous, banned or unethical form of treatment.

Another aspect that as parents you should be aware of is that Stem cell therapy is presently available in the following ways:

- As part of a clinical trial, where depending on the trial design you may or may not get randomized to either actually getting the stem cell therapy or be part of a control (i.e. receive no treatment) or receive a placebo (i.e. be given something harmless but not actually get stem cells). It is important to understand all aspects of the clinical trial design (including inclusion and exclusion criteria, protocols, materials and methods etc ) before enrolling for any clinical trial. The results of all clinical trials are published in scientific journals.
- As part of a therapy, which may be combined with a rehabilitation program or other treatments. Here, all the children will receive the Stem cell therapy as there is no randomization into control groups or placebo groups. This may or may not be a part of a study. Being part of a study means that the clinical, investigative data, improvements and adverse events will be analyzed and the results subsequently published in scientific journals.

### ***Suggestions***

Suggestions to help you make decisions about whether to consider stem cell therapy for your autistic child?

Now here are some suggestions on what you should do as parents:

There are two steps to this

### **Step one:**

- To decide whether to undergo stem cell therapy?

This is a decision that has to be taken by you yourself after understanding all aspects (the pros and cons) of the treatment. We must realize that for every choice we make there are consequences of two types. Good outcomes and not good outcomes. This is true for whether we make a choice to do something and even when we make a choice to not do something. So if we do stem cell therapy there is the possibility of good and not good consequences. A not good consequence could be a lack of improvement or some adverse event. But, if we choose to not do the treatment then too there are good and not good consequences. For example, a not good consequence of not undergoing the treatment is a progression of the condition. We hope that this book and this chapter in particular equips you with the knowledge to be able to make an informed choice. But the final call will still have to be taken by you.

### **Step two:**

- If yes then where to undergo the Therapy
- Which type of stem cell therapy to undergo?

Regarding which Stem cell center to take the treatment from, our advice would be that you get answers to the following questions when visiting or consulting with a Stem cell therapy:

#### **Question 1: Does this center have an Institutional Ethics committee?**

In India it is mandatory to have separate Stem cell ethics committees which are referred to as ICSCRT (Institutional Committee for stem cell research and therapy).

This is important since an ethics committee evaluates sanctions and monitors the work being done at the center. It ensures a system of checks and balances thereby ensuring patient safety.

#### **Question 2: Has this center published their results in peer reviewed scientific journals?**

This again differentiates genuine centers working with scientific and academic principles and values from those just set up for commercial purposes. The acceptance of papers for publication entails a process where other doctors and scientists review the data submitted and decide its merits and suitability for publication. This is called peer review and though not a guarantee, it does to some extent ensure that basic scientific and medical principles are being followed for the work that is being published.

#### **Question 3: Is special informed consent being taken?**

If yes you should ask for a copy of the consent and understand it before accepting to undergo the treatment. As per a Supreme court of India ruling, an informed consent should have the following information (i) Diagnosis (ii) Nature of treatment (iii) Risks involved (iv) Prospects of success (v) Prognosis if treatment not given (vi)



Alternative treatments. In any case, these are questions you have the right to ask these from the treating doctors. If the doctors openly and authentically answer all these questions then it is worth considering this center. If the doctors do not give you this information or get upset and angry if you ask questions or are not open and honest about what they do then we recommend that you do not undergo therapy at this center. All this is information that you have a right to and no doctor is doing you a favor by giving it to you.

**Question 4: What are the past clinical results of this center with reference to safety and efficacy? What improvements have been noticed in the previous patients treated?**

You should understand the improvements reported or published by the center and compare these to your own child and determine whether the symptoms that have been shown to improve are the ones in your own child that you want to see an improvement too. You should specifically enquire about any adverse events both minor and major as well as both short term and long term in the patients that have already been treated.

**Question 5: What types of stem cells are being used at the center? Which type of stem cell therapy to undergo is a very major question?**

- With our present state of knowledge we would advice extreme caution in considering embryonic stem cell therapy due to the risk of teratoma formation. It will take a few more years before the safety of embryonic stem cells is completely established.
- Umbilical cord derived cells are definitely safer than embryonic but one should know which company is manufacturing these cells and should obtain some more information on this company. Is it a reliable company and has good manufacturing facilities and practices and has this company taken the necessary regulatory permission and sanctions to manufacture these cells. In India permission is required from the Drug Controller General of India (DGCI). If these are in place then it may be alright to consider them.
- However, Adult stem cell taken from the patient's body (autologous) and which have not been manipulated outside the body are the safest of all types of stem cells. Unless there are other compelling reasons, these are the stem cells to be considered first.

So in summary our answers to the fundamental questions we started out with at the beginning of this chapter can be answered as follows:

**Question:** Does Stem cell therapy work for cerebral palsy?

**Answer:** Yes, it helps in producing various clinical improvements in the child.

**Question:** Are there any dangers or risks of the child's condition worsening?

**Answer:** No worsening in any of the children has been noticed so far.

**Question:** What improvements are likely to be seen in the patients with this therapy?

**Answer:** That it reduces spasticity, improves milestone development, voluntary movements/activity of hands and legs, improves oromotor activity (swallowing & speech), cognition, balance, reduces dystonia and involuntary movements.

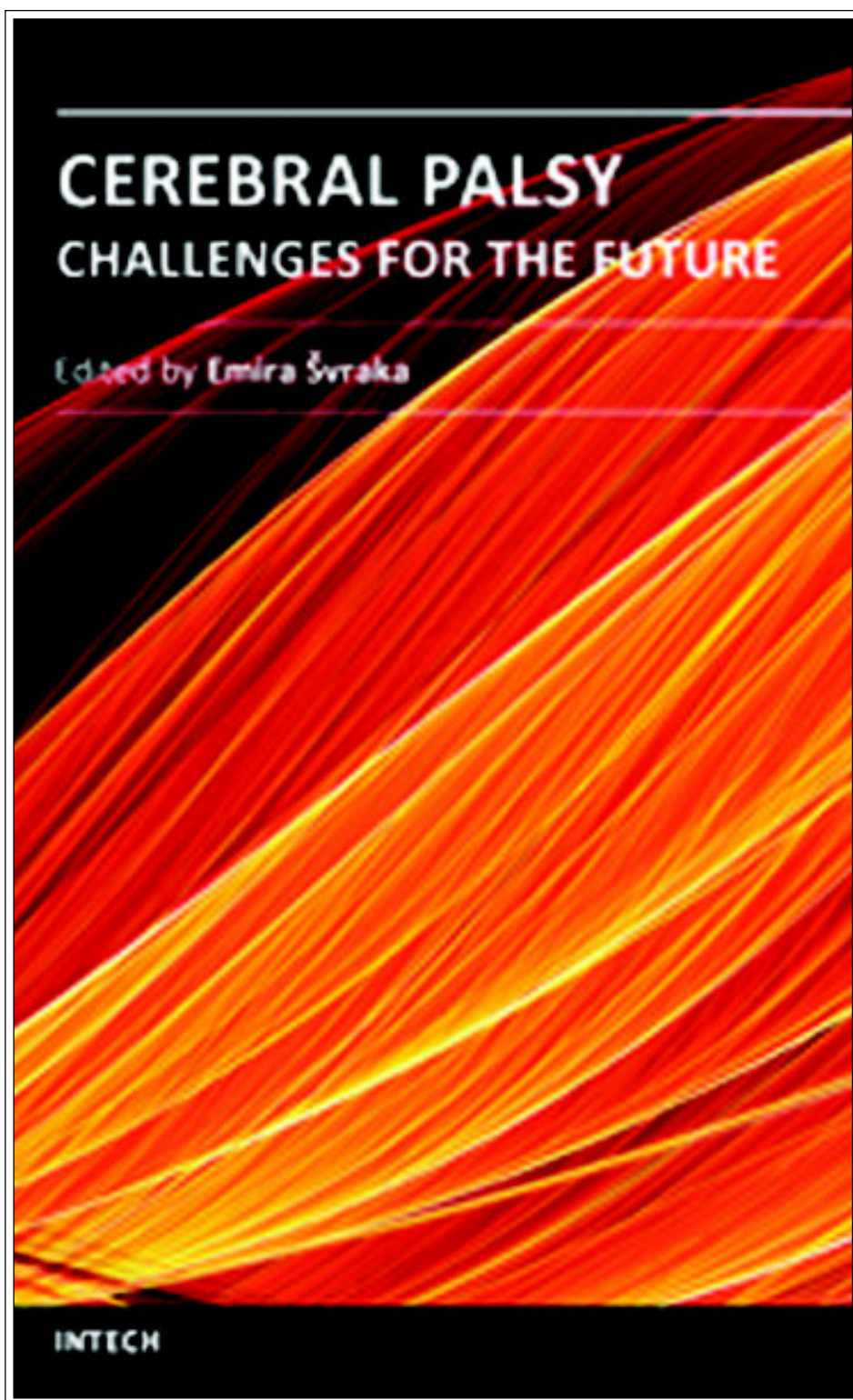
**Question:** How do I chose a good center for stem cell therapy and how do I know for sure whether the center I have chosen for stem cell therapy is working to high professional, scientific and ethical standards ?

**Answer:** Select a center that has an institutional ethics committee, that has published its results in scientific journals, where special informed consent is taken and all your queries are satisfactorily answered, that can show you documented improvements in its earlier treated patients as well as safety data and that is preferably working either with adult stem cells derived from the patient or umbilical cord stem cells obtained from a reliable company.

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(Full texts of these articles are available at [www.stemcellpublications.com](http://www.stemcellpublications.com)).

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**Chapter 7**

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**Stem Cell Therapy for Cerebral Palsy – A Novel Option**

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Alok Sharma, Hemangi Sane,  
Nandini Gokulchandran, Prerna Badhe,  
Pooja Kulkarni and Amruta Paranjape

Additional information is available at the end of the chapter

<http://dx.doi.org/10.5772/57152>

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**1. Introduction**

Discovery of stem cells by James Till and Ernest McCulloch in 1961, stands as one of the most remarkable medical-research achievements of the 20th century. This discovery provided a foundation for further breakthroughs in the field of stem cells. Sir Martin J. Evans along with Mario R. Capecchi, and Oliver Smithies were jointly awarded a Nobel Prize in 2007 for their contribution in introducing specific gene modifications in mice by the use of embryonic stem cells. Later in 2012, John B. Gurdon and Shinya Yamanaka were also jointly awarded a Nobel Prize for discovering that mature cells can be reprogrammed to become pluripotent cells. [1]

Ramon y Cajal in 1926 stated "Once the development was ended, the founts of growth and regeneration of the axons and dendrites dried up irrevocably. In the adult centers, the nerve paths are something fixed, ended, and immutable. Everything may die, nothing may be regenerated. It is for the science of the future to change, if possible, this harsh decree." [2]. It was a long-standing belief that cells of the central nervous system once damaged cannot be regenerated. The medical science of stem cells has finally made restoration of CNS possible which has changed the old concept of medicine. Not too long ago, this therapy was hamstrung by various controversies, ethical and moral issues. But, tremendous progress of research in this field has finally led to its translation from laboratory to innovative cellular therapies.

A variety of cells including embryonic stem cells, adult stem cells, umbilical cord blood cells and induced pluripotent stem cells have been explored as a therapeutic alternative for treating a broad spectrum of neurologic disorders including stroke, Alzheimer's, Parkinson's, spinal cord injury, cerebral palsy etc. amongst others. It is essential to select suitable cells depending on the nature and status of neurological dysfunctions to achieve optimal therapeutic efficacy. Along with the selection of cells, the route of administration also plays an important role to

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## 33. Hyperbaric Oxygen Therapy for Cerebral palsy

### **What is Hyperbaric Oxygen Therapy?**

Hyperbaric oxygen therapy is the inhalation of 100% oxygen at a pressure three times greater than normal atmospheric pressure in an enclosed, specialized designed, pressurized chamber. Under such conditions, more oxygen is taken up by the lungs and circulated into body tissues such as brain, blood, cerebrospinal fluid (CSF), etc. The body's healing process improves with more oxygen supply.

In Cerebral Palsy, the brain tissue is damaged so the blood supply is hampered making less oxygen available for recovery. Hence, for optimum function and development of the child, the brain requires sufficient quantity of oxygen. Studies have shown improvement in cognition, memory, gross motor function, fine motor function, spasticity, etc. in children with CP after administering them with HBOT.

### **How is the treatment performed?**

HBOT is primarily carried out in two ways, (i) in a monoplace chamber or (ii) in a multiplace chamber. The monoplace chamber only accommodates the patient while a multiplace chamber is a large chamber which can accommodate the medical staff along with the patient. HBOT is administered at 1-3 atm pressure for duration of 90-120 minutes. However, these parameters are not standardized.

The patients are placed in the sealed chambers and the pressurized oxygen is administered either through a mask or directly into the chamber. During the session, patient can sit or lie down comfortably and watch TV, read a book, play on a video game or even take a nap. An adult can also accompany the child if the chamber is large or there will be some provision for communication between the child and the adult from outside the chamber. Children are allowed to drink water to adjust to the ear pressures.

### **How does HBOT work in Cerebral Palsy?**

The underlying mechanism of action of HBOT is based on a theory which states that there are few cells in the damaged areas of the brain which are in dormant state. By

improving the oxygen supply, these cells are reactivated leading to functional recovery. Increased supply of oxygen to the brain also leads to formation of new blood vessels (angiogenesis) hence improving blood supply in the damaged areas. It also prevents further cell death (apoptosis) and reduces inflammation by producing anti inflammatory molecules.

By targeting these issues, HBOT helps in improving the affected functions such as cognition, memory, behaviour, speech, motor functions etc of these children. Recent studies have shown that HBOT mobilize stem cells/progenitor cells from the bone marrow. (8) These cells may help in forming new neurons, reversing the neurodegeneration (progressive loss of neurons) in cerebral palsy.

### **Are there any side effects of HBOT?**

When used according to the standard protocol, HBOT is a safe therapy. But nevertheless, some side effects may occur. Barotraumatic injury (in the ear, nasal sinuses, lungs and teeth), oxygen toxicity, myopia, cataract, claustrophobia, anxiety are a few side effects. Inhalation of high concentration of oxygen under pressure may also result in seizures. Prolonged treatment of HBOT may also lead to chest tightness and toxic pulmonary effects. (9)

### **Conclusion**

HBOT is a promising treatment but its results are not yet established. It requires a large number of sessions (40 sessions) to exhibit effectivity. It can be used along with standard treatment modalities. It is recommended that before deciding on the treatment you discuss the details of HBOT with the specialist doctor and to know its benefits for your child.

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**SECTION F :**

**View Points and Dilemmas of  
Patients and Parents**





## 34. Sand Dunes: A Word by parents

*"Encountering ups& downs are common in everyone's journey of life; happiness is based on how well you accept it, in the end you will be able to review how well you loved, how fully you lived and how deeply you let go"*

It was the year of 2002, and we were a happy family of three. Our daughter was 8 years old, my wife was a teacher, and I was dedicated to my official work but devoted to the society for charity and social work. That was a good time we enjoyed and our son Nadi joined the family in April 2002. He brought us heaps of happiness, as if we received an unexpected gift. Our daughter was walking on clouds with her baby brother.

Nadi was all smiles and giggles...he was a bundle of joy at home.

But it was not long after; when Nadi reached seventh month we noticed his head was not stabilized yet. We promptly consulted a pediatrician, and after several discussions among doctors they confirmed that Nadi was born with Cerebral Palsy. Upon understanding the magnitude of his condition to be, we fell into sadness, every bit of our happiness flew out the window. We were brimming with hopes and dreams, but all that was shattered and the pieces lost in the wind. We lost our courage, we were demoralized and disappointed. Not in a mood to even to talk to each other, to ask ourselves why it happened to us?

The entire house was in a puzzle, no one was able to advise us, to encourage us.

Not only did I have to lead my own life, but also my family's life.....I realized we should not bury our soles, we must not lose our strength, as Mahatma Gandhi Said.....

*"Be the change that you wish to see in the world"*



I regained my strength and woke up slowly; I asked myself why we are crying, why are we in grief. Neither Nadi nor any of us are responsible for his condition, he is not the only special child in the world, we are not the only family faced with this situation. So I decided to do something, but what to do?

I stood on a firm decision to do every possible thing to improve Nadi's life. I drew-up an action plan and brought forward the following.

1. Spoke to my Wife Shanthie and daughter Ramali, explained the whole situation, boost up their morality and strengthen their mindset.
2. Spoke to all our close relatives and tried to get their support as well.
3. Evaluate Nadi's condition; organize professional advice/ services accordingly and implement those instructions accurately.
4. Research for alternate treatment or management systems.
5. Educate ourselves about Cerebral Palsy, its impact on the person, level of conditions, people living with cerebral Palsy and their activity or progress or development. Also how other parents of C.P. children manage their life.
6. Learn to handle the child and give him the maximum comfort and care.
7. Equip the house with maximum possible way to carry out our task
8. Curtail social activity and leisure life to pay more attention towards Nadi.
9. Stretch my work to earn an extra buck to recompense upcoming additional expenditure.
10. Determined to stay together & work together to build Nadi's future together.....!!

With all that; we stood together with new courage to achieve our goal.

Immediately my wife, Shanthie, started physiotherapy with professional support and today she is quite competent to work even independently.

Every one of us frequently talks to Nadi, never letting him idle or be bored.

All our family members and friends came around, offering their love and affection for his utmost comfort. Our daughter was still a child, she missed lots of our attention but she extended no discontent, compromised many things in her life for the life of her brother. We exposed Nadi to the world and allowed him to grasp as many skills as possible from the surrounding and environment. We trained him

to watch Television built lots of homemade apparatus and bought some equipment and lots of educational toys to enhance Nadi's physical and mental activities.

We continue to get professional assistance regularly via home visiting physio and speech therapists, Nadi also went through two surgeries for tendon release, and consulted many alternative treatment centers in different countries.

When he was age appropriate, we enrolled Nadi in a special care school.

With all that Nadi was growing and improving slowly.

We, especially Shanthie, were confident that we will bring him to a stable level.

Even though the development was slow and limited we were very much contented.

In 2014, Nadi reached the age of twelve, he is very loving, jovial and a handsome young boy winning everyone's love and attention. Everyone is friendly with him and it is helpful for us as he gets special treatment at every corner.

News broke-out and Stem Cells research came in to lime-light, caught up by incurables.

As soon we came to know about the STEM CELLS treatment, we read a lot about it and collected as much as information such as type of treatment, act of work and

outcome, therapists & centers worldwide. While we read over a period of time; we built our confidence more on Stem Cells treatment.

Shanthie spent more time on this study to provide me with every necessary bit of information.

When Nadi reached 12 years of age we managed to collect a load of information and were well prepared to go forward with the Stem Cells treatment. After extensive research, we concluded that the Neurogen Brain and Spine Institute was the right place for us to attend for stem Cells treatment. We placed our trust on the dedicated team in Neurogen.

In March 2014 Nadi attended Stem Cells treatment at Neurogen, and then went through their extensive rehabilitation program in the care of their well-trained group of professional therapists.

Our stay in Neurogen was an entirely different experience. In addition to their utmost friendly hospitality; we had the golden opportunity to meet many children and their parents who had come for the Stem Cells treatment from various parts of the world. Some were first timers like us, and others were there for follow-ups. Everyone had something positive to say. Everyone was hopeful for better results. Some had a few ways to go before reaching their goal, but every comment demonstrated their gratitude to the Neurogen team and their Stem cells treatment as well as their rehabilitation program.

We came home with lots of hope. We started to continue our own home work with an exercise program that we learned in Neurogen. Also we continued with professional therapy.



*Nadira's Visit to NeuroGen*

It's been six months since the Stem Cells Treatment, and today we feel like that we see a light at the end of the tunnel. Nadi is showing lots of small changes in many areas which we have not seen before. We feel that he has gained his muscle strength, and talks more with better communication skills.

Nadi's life is changing.....!!!

***“Happiness is all about fulfilment of desire”***

We now have our smiles back and have started to think more positively than ever before, our confidence levels are up and we have high expectations of Nadi being on his feet soon...!!!

***“Almost all aspects of life are engineered at the molecular level, and without understanding molecules we can only have a very sketchy understanding of life itself” – said by: Dr. Francis Harry Compton Crick.***

## 35. Inspiring Stories of Patients With Cerebral Palsy

I was born in an underdeveloped family in 1981. I was second child of my family. My mother lacked family support and guidance during my delivery. She also didn't get any such relief to enjoy after my delivery. After sometime that became a crucial time for her to take the decision of stepping out and help out my dad in bread winning. In all such times it was not realized that I am not showing any movement or development in my body. After it was realized I was taken to several hospitals where every doctor came up with different views, opinions and treatments but nothing worked out. In 1983, my parents came in touch with Dr. Maya Nanawati when I was 2 years old. At that time it was discovered that I am suffering with Cerebral Palsy which has effected 60% of my body below neck. After that I was given physiotherapy treatment to retain my body's current position.

There was a time when it was suggested by the doctor as a treatment to dump my body in some beachside sand till neck at least for 2 months continuously, this treatment was suppose to warmup my body muscle and increase my blood circulation which will further improve the mobility of my body. Considering it a part of new hope my family decided to go for the said treatment whereby it was mutually decided that my father will take me to Chowpatty everyday for 2 months. My dad was working in a engineering factory that time. When my dad approached his office people for 2 months leave so that he can concentrate on my treatment, it got declined and he was offered to make a selection between job and my treatment. No doubts being a true father he chosed my treatment as his first preference and left his job. At that time my mother also played a very significant role as she ran the house solely that time including my medical expenses which was much more than my family income.



Then came the time when I was suppose to get admitted in the school . My parents and doctors were not sure at that time whether I should be admitted to a special school with mentally sick students or a normal school with normal students. But later after lot of evaluation it was decided that I should be admitted to a normal school. But it was hard to get admission for a special child in a normal school, but my mother didn't loosed her hope and decided to meet the principal of School Himalaya High School personally. When she approached to meet her(Principal) it was found that she (Principal) had met with an accident. So my mother decided take me to her residence and try to convince her to get me admitted in her school. So in 1987, so my school journey started. School life was extremely amazing. I was able to enjoy lots of experiences and equally sacrifice many like going to camps, picnics, etc. During my school I was able to secure lots of prizes and rewards. Meanwhile my treatment was also carried out successfully . In 1992 I first underwent soft tissue release surgery, where the doctors tried to improve my body structure so that I could walk without support. However it was successful too to a certain extent . And accordingly with all family and doctor support I completed my school successfully in 1999. In the meantime , I also loosed my father when I was just 14 . My mother then stood up courageously and took my and sibbling's responsibility. My Sister also played a very crucial role in my studies . She was the one who used to assist me in toileting during school time being in the same school . Even in my higher education she was the one who used to take me various centres for examinations and follow up with universities . I attended my college till 12th in Science and then went for distance education as no degree college was nearby my place. I completed my graduation in 2003. As I was studying at home for 3 years and there was minimal body movement , my body got stiffened day by day thereby losing my mobility . I was completely on chair that time, I was not even able to move till toilet. Then my mother again took to my therapists Dr. Maya Nanawati who directed us to Dr. Atul Bhaskar who suggested for soft tissue release operation for the second time again. Accordingly I was operated in November 2004 where I was given second opportunity to live my life , as this operation improved my mobility and I was able to walk with walker.

After this situation , I started my career in 2006 with metlife india insurance company as telemarketing executive. During that period the company also imparted me with IRDA training which helped to become Financial Advisors of the prospects. As this was a free lancing job with no specific regular income I went for a career with Centurion Bank of Punjab in 2007 . After the merger of Centurion Bank of Punjab with HDFC Bank I was then absorbed in HDFC in the same year, but unfortunately I loosed my job due to recession in 2009. Then I started working with Janaseva Bank in the same year where I am still continuing to work . After I got a stable job in Janaseva Bank I decided to go for higher studies MBA in 2012.

Thus with all such stages in my life I am living a independent life right now.

Also with complete support of my family and great hardworkship of my mother I was able to stand on my feet and be with others shoulder to shoulder.

**Mother's Statement :**

Every special child is more near to god. They always a X-factor spark in them . If identified and nourished these sparks can nourish great fruit.

So I did with my daughter , I identified the potentials in her nourished those potentials and took a very special care of her at every stage.

I tried to rectify the deviation between what less god gave to her and what extra I can give to her to cover up that scarce part so that she don't regret of loosing anything due to her disability .

Explaining the same with an example , whenever there used to be a school picnic in her school I never let her go as I was always concerned about who will take care of her , she used to regret a lot about not being able to attend school picnic ,so to reduce this regression of her I used to bring her all the stuffs like chocolates, wafers, fruits , cola drinks , etc to reduce her pains. I used to take an off and used to spend my entire day with her that day, so that she don't feel loneliness.

Right now also I always try to understand her emotions as she is spending a life little different from others.

Thus I request all parents of the special child, please identify the potentials in your child , please try to explore their talents.

If taken a due care these children have the potential to do wonders.



## 36. Planning a Second Pregnancy

*Contributed by- Dr. Sriram Gopal*

Being a parent to a child with cerebral palsy brings with it a whole horde of worries and responsibilities. Some of you might be contemplating a second pregnancy; and may have many unanswered queries. Let us help you with some of those.

### **Can I get pregnant again..is it safe ... can it recur?**

The risk of incidence of CP is 1-2 in a thousand. Genetic causes account for less than 2% of the cases. The other causes may not be recurrent, but studies have shown that there is a 6-9 fold increase in the incidence of CP in case of an affected sibling. "6-9 fold" appears large in terms of percentage; but it translates to an incidence of 0.6-1%. With due precautions for the preventable causes, this incidence can be reduced in individual cases.

### **When can I get pregnant again?**

A very short interval between 2 pregnancies increases the risk. But there is no statistical consensus about the interval between 2 pregnancies. A pregnancy can be attempted once you are physically and mentally prepared for the same.

### **Can anything be done to prevent it...prenatal/antenatal/intrapartum/postpartum?**

- Not all the causes of CP are known or preventable. However, there are certain associated factors which if prevented can help reduce the risk of CP in the child.
- prematurity
- low birth weight
- meconium aspiration syndrome
- birth asphyxia
- low blood sugar in the baby
- infections
- injuries, etc

Here are some suggestions to minimise the risk of recurrence

**Prenatal:**

1. Maintain adequate time gap between pregnancies
2. Avoid smoking, alcohol; they increase the risks of preterm labour and low birth weight
3. Control medical conditions like hypertension, diabetes, infections before attempting pregnancy
4. Optimise your physical condition

**Antenatal:**

1. Regular antenatal checkups with your obstetrician
2. Prompt treatment on infections if any like UTI, vaginitis etc
3. Nutrition
4. Hygiene
5. Optimal treatment of medical conditions in pregnancy viz . gestational diabetes, pregnancy induced hypertension, anaemia etc
6. Avoid strenuous exercise/physical activity

**Delivery:**

Delivery should be ideally done in a hospital where adequate facilities for delivery, surgical intervention and neonatal care are available

**Post-delivery:**

1. Ensure adequate nutrition of the child
2. Prompt and timely treatment of conditions like jaundice
3. Avoid infections in the child, by maintaining proper hygiene
4. Prompt treatment of infections if any
5. Guard against any kind of trauma to the child

The above precautions should be taken till the child is at least 2 years old

**Do I need specialised obstetric care? Do I need to deliver in a HDU/ tertiary care unit?**

Not mandatory, provided adequate care is taken as mentioned above.

**Should I insist on a paediatrician during delivery?**

It is definitely advisable to have a paediatrician stand-by, to deal with any emergency

### **Is the obstetrician to be blamed for the condition of my child?**

Earlier it was widely believed that lack of oxygen during delivery was the cause of most of CP. But recent reports state that less than 10% of CP cases are caused by difficult deliveries. The major cause is prematurity, low birth weight and birth defects. So, it follows that good obstetric care goes a long way in reducing the incidence of CP.

### **Do I need to go for an elective CS?**

As mentioned earlier, difficult delivery is not a cause of CP, so an elective caesarean section is not warranted

### **Should I refuse consent for instrumental delivery?**

Instrumental delivery (forceps or vacuum) have not been proved to be a direct cause of CP. The usual indications for instrumental delivery are either prolonged labour or hypoxia of the baby, which by themselves can cause CP.

### **Can I know if my new born has cerebral palsy?**

CP cannot be diagnosed at birth

### **Does my newborn need to take any medication to prevent the occurrence of CP?**

No medication can prevent CP per se. but proper immunization, infection control and nutrition can go a long way in preventing conditions which can result in CP eg. Encephalitis, meningitis etc

### **Should I go for cord blood/umbilical cord banking?**

Regarding umbilical cord blood storage, the potential for use in the future is huge. Having said that, the must store scenarios are:

a) Haematopoietic disorders in siblings. cord blood can be a potential source of stem cells, instead of allogenic bone marrow.

b) Pregnancy complications... In our practise now, we have increasing seen cases of CP and autism are ON THE RISE. cord blood stem cells is a good source again, of stem cells.

In absence of the above, UCBB storage would be more like an insurance policy, we hope never to use it!!

In absence of cord blood cells, autologous cells(bone marrow derived) are available and infact a much readier and usable source . If money /finances is not an issue, then cord blood storage can be chosen.

## **37. Frequently Asked Questions**

### **1. Can my child get better?**

Cp refers to a permanent condition and problems related to this condition remain throughout the lifetime, however these children can cope up with the condition as they grow. Various treatments available often bring out improvement in the condition, though it is not a cure.

### **2. Can my Childs condition deteriorate?**

No your child's condition won't deteriorate further unless there are any underlying factors like any illness or infection, may cause the child's progress to come to stand still.

### **3. Why do the muscles become or why deformities happen?**

Stiffness in the muscles is due to spasticity, contractures or both. It is difficult to distinguish between spasticity and shortening and during growth spurts the child's bones will grow more rapidly than muscles, which lead to tightening and activities like walking or standing makes it more apparent. Treatment for spasticity and shortening is different.

### **4. Can emotional stress hinder my child's progress?**

Yes it can, especially when the child is pushed or forced to achieve a skill, they may react by becoming stubborn or may refuse to cooperate, and this may certainly be a reason for lack of progress but which actually doesn't mean that the child's condition is deteriorating. But if the child loses previously acquired skills, then it is important that you should discuss it with your therapist or doctor.

### **5. Will my child learn how to walk?**

Every child with cerebral palsy is different from each other, and so it is not possible to come to a conclusion. Unless the child has been observed over time by the paedrician and therapist. As a parents you are always curious and worried about your child's walking. However children with mild cp can learn to walk

independently, children with moderate cp may walk with a stick or walker and children with severe cp are generally wheelchair.

## **6. Will my child learn how to talk?**

Yes and no. Children with cp may not have any difficulties to talk ,while few may have controlling the movement s around the mouth or delay in developing learning skills. Children with cerebral palsy will need help from a speech therapist to learn how to use alternative methods of communication or develop speech.

## **7. Can my child be independent?**

The aim of all the treatment is to encourage these children to learn to be as independent as possible. As parents it is always important for you to encourage your child to do as much as possible. Children with mild cp may not have any problems achieving independence but the ones with severe cp may require assistance from others throughout their lives.

## **8. Can my child develop behavior problem?**

Some children with cerebral may have behavioral problems, which can be difficult to manage. They may also be frustrated, due to inability to move, talk. Clinical psychologists play an important role in addressing behavioral issues and help develop and motivate and encourage child to feel good about them and be happy.

## **9. Can my child lead a normal expectancy?**

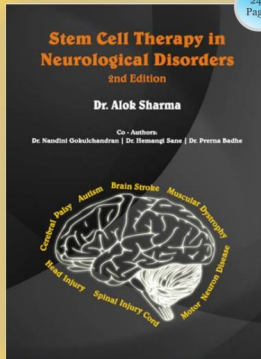
Most children with cp are healthy and lead a normal life. Children with severe brain damage associated conditions such as epilepsy may be a risk of reduced life expectancy.

## **10. Will my next child also have cerebral palsy?**

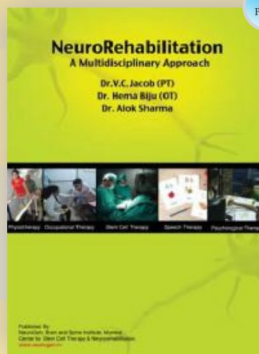
It is extremely unlikely for your second child to have cerebral palsy. Please ask your doctor to guide you about genetic counseling and future care in pregnancies.

# Other books published by NeuroGen Brain and Spine Institute

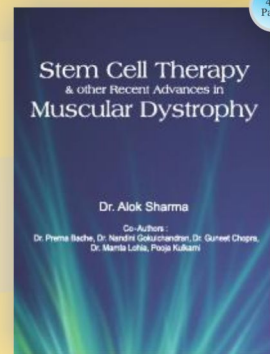
## Stem Cell Therapy in Neurological Disorders 2nd Edition



## NeuroRehabilitation- A Multidisciplinary Approach

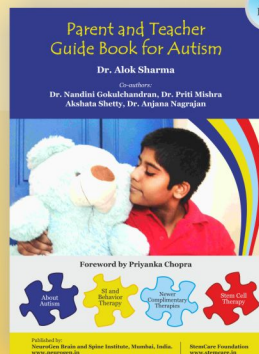


## Stem Cell Therapy & Other Recent Advances in Muscular Dystrophy

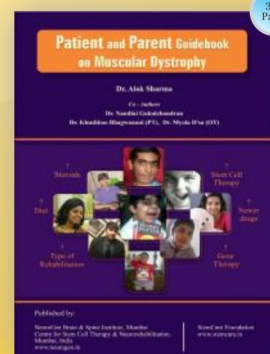


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## Parent & Teacher Guide Book for Autism



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