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ENLIGHTENMENT FOR PARENTS AND CAREGIVER-TO RAISE A CHILD WITH CEREBRAL PALSY

S.K.Mohanasundhari*

Faculty AIIMS Jodhpur, College of Nursing, Rajasthan, India.

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ABSTRACT

Cerebral palsy is an umbrella term for a group of neurological disorders that appear early in life. They permanently affect the individual's ability to coordinate movement. Abnormalities in the brain cause cerebral palsy, although often, no specific cause can be found. Cerebral palsy is usually not progressive; that is, it does not tend to get worse with age. But the emotional, physical, social and economical burden of the parents and care giver will worsen day by day because of the nature of the illness. The child with cerebral palsy needs continuous care and observation. That locks the parents or caregivers from other activity and increases their stress level. How far it is important to give meticulous care to cerebral palsy child, the same way self care of parents and caregiver also is important to be free from severe stress and its consequences. The review article focuses on tips for parents or caregivers of child with cerebral palsy to overcome the issues faced by them.

INTRODUCTION

Cerebral palsy also known as CP is a condition caused by injury to the parts of the brain that control our ability to use our muscles and bodies. Usually the greater the injury to the brain, the more severe the CP. However, CP doesn't get worse over time, and most children with CP have a normal life span. Depend up on the level of neurological deficit the dependent level of the child will vary like completely dependent, partially dependent, partially independent and complete independent. CP can be mild, moderate, or severe. Mild CP may mean a child is clumsy. Moderate CP may mean the child walks with a limp. He or she may need a special leg brace or a cane. More severe CP can affect all parts of a child's physical abilities. A child with moderate or severe CP may have to

use a wheelchair and other special equipment. Sometimes children with CP can also have learning problems, problems with hearing or seeing (called sensory problems), or intellectual disabilities. There are three types of CP are:

Spastic cerebral palsy

Causes stiffness and movement difficulties

Athetoid cerebral palsy

Leads to involuntary and uncontrolled movements

Ataxic cerebral palsy

Causes a problem with balance and depth perception. Since cerebral palsy affects muscle control and coordination, even simple movements like standing still are difficult. Other functions that also involve motor skills and muscles such as breathing, bladder and bowel control, eating, and talking also may be affected when a

Corresponding Author

S.K.Mohanasundhari

Email: -roshinikrishitha@gmail.com

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child has CP.

When a parent notices a child having difficulty relating to achieving independency during the process of growth and development of their child, it's often more painful than if they were going through it him or herself. Gaining self image and acceptance for their child with cerebral palsy in the society will be most difficult task for parents. Although many parents are faced with the prospect of a child that has difficulty gaining acceptance from peers, those who have children with special needs cope with a different set of circumstances. Having a child with CP is exhausting and frustrating at times for kids and for parents; we don't always have the energy to educate other people about CP. Parents with poor coping mechanism used to avoid interacting with society due to fear of criticism and other possible question raised. Day by day they feel guilty and stress occupy them completely. On other hand child with complete dependency gives more burden on parents time and energy spend on them. This cause additional stress to parents or caregiver. But with all these issues it is also important to for the parents and caregivers to take care of themselves physically, mentally and socially. There are so many facilities available to care cerebral palsy children which reduce economic and physical burden on parents and caregiver. The following section discuss deeply about enlightenment for parents and caregivers of child with cerebral palsy.

Enlightenment for parents and caregivers

- Learn about CP. The more parents/caregiver know, the more they can help themselves and their child. Emphasize the positive. When people hear the words "neurological injury" or "brain injury" they may assume CP is progressive or even life-threatening. It's helpful to say up front that CP is not a degenerative disorder.
- Love and play with child. Parents should treat their CP child as a child without disabilities. Take child to different places, read together, have fun.
- Learn from professionals and other parents regarding how to meet child's special needs, but try not to turn parent's lives into one round of therapy after another.
- Keep it simple. Parents often learn a great deal about CP while consulting specialists and determining options for therapy. But caregivers, acquaintances, and parents of other children don't need medical information; it's fine to share the basics directly and factually.
- Ask for help from family and friends. Caring for a child with CP is hard work. Parents can teach others what to do and give them plenty of opportunities to practice while they take a break.
- Keep informed about new treatments and technologies that may help. New approaches are constantly being worked on and can make a huge

difference to the quality of child's life. However, parents be careful about unproven new "fads."

- Learn about assistive technology that can help child. This may include a simple communication board to help the child to express needs and desires, or may be as sophisticated as a computer with special software.
- Focus on abilities. A child's disability may re-define aspects of their interactions with others. That alone is something that will make a child more noticeably different than his or her peers. They may have impaired speech, or move differently, have difficulty eating, or use assistive devices. But this doesn't change a child's capacity for interacting with others. They can still speak and express ideas in many cases. They may have limits on their movement, but they can still enjoy a beautiful day outside. When these commonalities are stressed at home, a person with disabilities can see themselves as part of a larger world with all types of people.
- Patents need to have patient, keep up hope for improvement. The child, like every child, has a whole lifetime to learn and grow.
- Work with professionals in early intervention or in school to develop an individualized family service plan or an individualized education program that reflects your child's needs and abilities. Be sure to include related services such as speech-language pathology, physical therapy, and occupational therapy if the child needs these. Don't forget about assistive technology either.
- Let others know how to describe your child, i.e. a "child with disabilities" rather than "a disabled child." It's more than political correctness. Person first language reinforces that our kids do everything other kids do, just in unique ways.
- Find social opportunities early, and often. One way children can meet potential friends and begin the process of socialization is through activities and interaction with their peers. Find activities that a child may enjoy and that fit into his or her skill set. The simple process of getting to know other people through engagement and common interests helps the child see that he or she is capable of making friends. This serves as a powerful lesson going forward because a child will be less likely to develop social anxieties that can derail adult relationships down the line. For guidance with age-appropriate social development, read Erik Erikson's Theory on Psychosocial Development.
- If a child rejects your child, it's his or her problem. Rejection is a part of life for everyone, not just people with disabilities. It's something that will happen to everyone, multiple times, throughout a lifetime. It's natural that someone with disabilities would believe the rejection occurred because he or she has a disability, but that's not always the case. Let a child know that when



- Rejection occurs, it's more about the other person than it is about them. At these times, reinforce in your child a sense of their self-worth. For example, simply stating, "Their loss" can do wonders. Or, "That's a shame; they really could have had a wonderful friend in you, if they would have taken the time to understand you better." This establishes the rejection towards the misunderstanding, and not a rejection of your child.
- Establish limits. All children need limits. In an attempt to fit in with other children, a child may want to take part in activities that are not safe, or are otherwise unreasonable. Setting limits will help children understand that relationships – especially those that begin in childhood – should be unconditional and free of pressure within reasonable limits. Be careful, though, not to underestimate your child's ability to achieve beyond your perception of their capabilities. Children never cease to amaze, especially those empowered to do so.

Fig 1. Tips for Parents



Enlightenment for teachers

- Learn more about CP: The more parents/caregiver know, the more they can help themselves and their child. Emphasize the positive. When people hear the words "neurological injury" or "brain injury" they may assume CP is progressive or even life-threatening. It's helpful to say up front that CP is not a degenerative disorder.

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- This may seem obvious, but sometimes the "look" of CP can give the mistaken impression that a child who has CP cannot learn as much as others. Focus on the individual child and learn first and what needs and capabilities he or she has.

- Tap into the strategies those teachers of students with learning disabilities use for their students. Become knowledgeable about different learning styles. Then teacher can use the approach best suited for a particular child, based upon that child's learning abilities as well as physical abilities.

- Be inventive. Ask yourself (and others), "How can I adapt this lesson for this child to maximize active, hands-on learning?"

- Learn to love assistive technology. Find experts within and outside of school to help you. Assistive technology can mean the difference between independence for student or not.

- Talk candidly with student's parents because parents are experts. They can tell you a great deal about their daughter or son's special needs and abilities.

- Effective teamwork for the child with CP needs to bring together professionals with diverse backgrounds and expertise. The team must combine the knowledge of its members to plan, implement, and coordinate the child's services.

CONCLUSION

Once parents and caregivers have adequate knowledge guidance and facilities regarding care of child with various degree of cerebral palsy will increase their self confident level. That keep motivating them to be excellent caregiver. If parents employ some methods designed to give their child an opportunity to reach out to others they can avoid unfortunate situation.

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CONFLICT OF INTEREST:

The authors declare that they have no conflict of interest.



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