What is Cerebral Palsy?

- *Cerebral* means having to do with the brain and *palsy* means problems or weakness with using the muscles.
- Cerebral palsy (CP) is caused by abnormal brain development or damage to the developing brain.
- CP affects a person’s ability to move and keep their balance and posture.
- Often the condition happens before birth (pre-natal) or shortly after birth (post-natal) and sometimes due to complications during birth (peri-natal).

Editor’s Notes

Welcome to our first newsletter.

Every Friday, the pubs in Sandton are filled with traders who are like, “I got this big problem. What am I going to do? I have to spend four million rand by Monday. What am I going to buy, an island?” and you’re like, *Whoa, this is a twenty-year-old trader, he has to cash in, he has to turn his numbers into something real, and he has two days to do it, and he doesn’t really know what he wants!*

One of the most interesting books I’ve read lately is something on reality and capitalism. It’s easier for people to imagine the end of the world then it is for them to imagine the end of capitalism. What’s driving stuff here? It’s not ideas of freedom and equality. It’s money and fame.

The values of freedom and equality are at the heart of what we campaign for. People with disabilities are denied these fundamental rights by a inaccessible environment. Many cannot access the very basic things that are required to make a living – public transport and access to buildings and other services.

The NCPPDSA works hard to improve the lives of some of the most marginalised people and children in South Africa. We are the biggest fundraiser for persons with disabilities in South Africa.

Our newsletter aims to educate about all the different aspects of disability and our various programs to improve lives and help rebuild livelihoods affected by disability.

Our first issue deals with Cerebral Palsy, what it is, its prevalence in South Africa, and what care and interventions are available.

More on 2
Many people with CP also have related conditions such as intellectual disability; seizures; problems with vision or hearing, or speech, changes in the spine; or joint problems, e.g. contractures.

CP is normally classified according to the main type of movement condition involved. Depending on which areas of the brain are affected, one or more of the following movement conditions can occur:

- Stiff muscles (spasticity)
- Uncontrollable movements (dyskinesia)
- Poor balance and coordination (ataxia)

CP is the single largest cause of childhood disability.

Cerebral Palsy in South Africa

Children with cerebral palsy living in poor and rural areas in South Africa are a particularly neglected and underserved group. Although they qualify for government assistance in the form of “Care Dependency Grants”, this money is usually the family’s only source of income and not all the money is spent on the child. Caring for a child with cerebral palsy involves many additional costs not associated with non-disabled children.
Care and Interventions for Persons with Cerebral Palsy

Although cerebral palsy is a lifelong disability, there are many interventions that can help reduce its impact on the body and the individual’s quality of life. An intervention is a service that aims to improve the condition of cerebral palsy and the day-to-day experience of the person living with it.

Children with cerebral palsy should be supported by a team of professionals including health professionals and community-based support services who work together to help the child and family reach their goals. Ideally CP assessments should be done by a multi-disciplinary team (MDT) consisting of a medical doctor (assessment, diagnosis, medication, surgical intervention), occupational therapist, physiotherapist, speech therapist, audiologist, dietician (feeding, growth monitoring), social worker (grants, counselling) and psychologist.

Access to CP services at the primary health care level depends entirely on the available medical and rehabilitation service and skills at the primary and secondary health care level in a particular area and this varies between provinces. Usually rural communities do not have experienced medical and therapeutic staff trained in the assessment and management of CP. Overall there is a severe lack of rehabilitation therapists in South Africa for managing CP
in the public sector. With 38% of the country’s population living in rural areas and mainly dependent on clinics at primary health care level, all aspects pertaining to the care and rehabilitation of children with CP are often severely neglected.

The NCPPDSA and Persons with Cerebral Palsy
Coming to South Africa! Advanced Biomechanical Rehabilitation (ABR): A life-changing new technique in the rehabilitation of children with CP

The ABR technique is designed to specifically address weak soft tissue and connective tissue structures. It is a home-based program that is taught to parents or care givers and then practiced 30 minutes to one hour per day in the home environment. It works by improving the overall quality of the body’s connective tissue system. Through a specialised method of repetitive application of pressure, an equally repetitive stimulation of the soft tissues is achieved. The body reacts to this stimulus, by remodeling and regenerating the areas that are being addressed.

Metabolic functions are improved. General skeletal alignment and positioning ensues, restoring mobility and allowing for new or renewed motor functions. Cognitive advancements, being dependent upon the general health of the individual, also follow.

Recent prospective studies presented in 2012 at the International Cerebral Palsy Conference in Pisa, Italy have shown that ABR significantly improves quality of life and function in children (between the ages of 5 and 18 years) with the most severe forms of CP. This is very encouraging, since few therapies are able to change the course of CP after the age of 5.

Increasing the quality of life and function in a person with severe CP has far reaching effects. Family joy and coherence improves as the burden of care of the sick family member is decreased. Nursing intensity decreases (through improved swallowing, sleeping and metabolic functions), thereby decreasing medical costs. The affected individual is able to participate more in life experiences new ways to observe and participate in life.

Follow the link below to watch a short video illustrating the profound benefits of the ABR method on children. This is just a small sample of children, but every child with CP, especially those who have severe CP, will benefit from the ABR Method. Watch their faces and see how the whole child benefits.

Supporting the NAPCP
The National Association for Persons with Cerebral Palsy (http://www.napcp.org.za) is an affiliate of the NCPPDSA with the NCPPDSA playing a strong supportive role in respect of the NAPCP who in turn have many schools for children with CP and provincial associations for persons with CP under its wing. In an extensive way cerebral palsy associations are involved in the care and rehabilitative services required at local level and as such offer a vital safety network of intervention to persons with CP.

Casual Day
The NAPCP is also a national beneficiary of The NCPPDSA’s Casual Day, the biggest fundraiser for persons with disabilities which has been running for 19 years.

The Game / Vodacom Wheelchair Project
The Game / Vodacom Wheelchair Project, facilitated by the NCPPDSA, has been supplying thousands of
wheelchairs to school going children with CP and other disabilities since 1998. In 2013 alone the project has provided 254 children with wheelchairs through the generous social investment of Game and Vodacom.

The Buggie Project
The NCPPDSA is now seeking a corporate partner for its “Buggie Project”. For children with CP when it comes to wheelchairs, one size does not fit all. A buggie is a specialised wheelchair with seating equipment appropriate to the specific individual to offer an optimal seated position for proper postural support and to allow a position from which the child may engage in functional activities. Standard, non-adjusted wheelchairs are detrimental to many children and persons with CP, causing not only great discomfort, but exacerbate common problems such as pressure sores, the progression of deformatories and contractures, respiration and digestion difficulties and overall instability.

Nappy Run
Nappy Run (http://www.nappyrun.org.za) is another proud NCPPDSA campaign. Nappy Run is first and foremost a public awareness raising campaign about the prevalence and manifestation of child disability in South Africa and the conditions children with disabilities are exposed to. (The vast majority of our country’s children with disabilities are also poor!). But Nappy Run also raises hundreds of thousands of nappies (diapers) from the public and corporate sector for children with disabilities, including children with CP. Children with disabilities have a much higher need for nappies than other children and often they also need to use nappies up to an advanced age. With nappies being expensive, parents often can’t afford them resulting in children being subjected to the discomfort, degradation and humiliation of having to go without nappies and seeing a child “wet” is quite a common occurrence.

Research
The NCPPDSA has conducted extensive research into Government financial support of day care centres for children with disabilities. The findings of this survey are being used to advocate for an improved dispensation of Government financing and support of these informal, community based centres for children with disabilities. Suffice it to say that Government’s current levels of financing of these centres are meagre and the children are being cared for under conditions of severe shortages of resources and adequately trained personnel.

The National Association for Persons with Cerebral Palsy
In 1955 NCPPDSA decided to establish a National Division for Cerebral Palsy to deal with issues and services regarding Cerebral Palsy.

The NCPPDSA is proud to have a very close partnership with the National Cerebral Palsy Association as well as schools and centres which render services to persons with cerebral palsy. We jointly advocate for the rights of persons with Cerebral Palsy and render services to adult persons and children with Cerebral Palsy.

We congratulate SANDY HEYMAN, a well known disability rights activist who has recently been elected as national chairperson of the NACP. Sandy, who has CP herself has announced her
personal commitment to support not only persons with Cerebral Palsy, but also their families.

As the founder and Director of People for Awareness on Disability Issues (PADI), Sandy has become a familiar public face and voice because she has never allowed her physical disability to limit her. She has achieved some extraordinary goals - including a 50 mile walk in her own wheelchair, a hot-air balloon ride, and even parasailing.

In her position as Director of PADI, an organisation established by people with disabilities for people with disabilities, Sandy raises public awareness. On a more personal level she teaches the community especially children to overcome prejudice and fear and create the awareness that disabled people are first and foremost people. She also encourages disabled people to improve their self-image empowering them to take their rightful place in society.

The NCCPDSA on the web

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