

CEREBRAL PALSY

INCLUSIVENESS

“ With tremendous burdens often come enormous gifts. The trick is to identify the gifts, and glory in them.”

(Dr. Maya Shetreat-Klein)

The Aim of Scouting is to promote the development of individuals, enabling them to grow and take their place in society as active citizens. As we move forward with the Canadian Path we are much more aware of each individual's personal progression, inclusive of their varying abilities. This inclusiveness within Scouting uniquely positions us to play an important role in modifying community attitudes and behaviour towards individuals with identified needs; it starts with Scouts.

Please use this guide for a better understanding of youth with Cerebral Palsy (CP); how as Scouters, we can make a difference through simple interventions, program modifications and knowing where to get help when needed.

DESCRIPTION

A condition marked by impaired muscle coordination (spastic paralysis) and/or other disabilities, typically caused by damage to the brain before, during or shortly after birth. This damage affects the message from the brain to the muscles (not the muscles themselves), making movement and posture difficult.

CHARACTERISTICS/BEHAVIOURS

- Youth with CP may be slower in achieving important developmental goals, such as learning to walk or speak, but this will vary from person to person
- Youth with CP tend to have problems with their muscle tone (the unconscious ability to contract or relax muscles as needed) resulting in uncoordinated and uncontrollable movements
- **Hypertonia:** increased muscle tone, which can make the youth appear stiff or rigid
- **Hypotonia:** decreased muscle tone, which makes the youth appear floppy
- Youth with CP tend to favour one side of the body over the other, which can make their posture appear unusual

- May have slow or slurred speech, or may not be able to speak without the aid of a communication device
- Youth may have poor saliva control
- Very wide range of degrees of severity, varying from youth who appear regular functioning but may not be able to run quite as well as others to totally wheelchair bound youth who need help with almost all activities
- Possible exaggerated startle reflex, meaning sudden loud noises can cause significant distress, may also be effected by temperature changes, lights, taste and smell
- Wicked sense of humour

There are several forms of CP — below is a brief description of the various forms.

Spastic Hemiplegia

- Youth with Spastic Hemiplegia, will have muscle stiffness (spasticity) on one side of their body; this is normally limited to the hand and arm, but sometimes also affects their leg
- Spastic hemiplegia may also cause the youth to develop an abnormal curvature of the spine (scoliosis)
- They may have problems speaking, but their intelligence should not be affected by the condition
- Some youth with Spastic Hemiplegia also experience epileptic seizures

Spastic Diplegia

- In youth with Spastic Diplegia, the youth will experience muscle stiffness in their legs
- This may cause difficulty walking, and they may need aids such as leg braces or a walking frame
- Communication skills and intelligence should be unaffected

Ataxic Cerebral Palsy

- In Ataxic Cerebral Palsy, the youth's balance and depth perception will be affected (depth perception is the ability to judge where objects are in relation to your position)
- The youth may appear clumsy and uncoordinated and have problems with activities that require precise movement, such as writing or tying a shoelace



- May also experience tremors in their hands (involuntary shaking), especially when they are trying to reach for an object
- The youth's communication skills and intelligence should be unaffected

Athetoid or Dyskinetic Cerebral Palsy

- If the youth has Athetoid Cerebral Palsy (also known as Dyskinetic Cerebral Palsy), they will experience both increased and decreased muscle tone. This means they often make apparently random and uncontrolled body movements. They will probably have problems maintaining their posture
- Their speech will be affected as they have difficulty controlling their tongue and vocal cords
- The youth may also have problems with eating and drooling
- Intelligence is not normally affected in youth with Athetoid Cerebral Palsy

Spastic Quadriplegia

- Spastic Quadriplegia is the most severe type of CP, caused by extensive damage to the brain
- The youth will have a high degree of stiffness in all their limbs, and may be unable to walk
- At the same time, their neck muscles will be very loose and they may have problems supporting their head
- They will find speaking difficult, and may have moderate to severe learning difficulties, but this will vary from person to person
- Frequent epileptic seizures are common in youth living with Spastic Quadriplegia

IN A SCOUTING SITUATION

- Scouters should educate themselves about the youth's condition and prepare for the future by asking the right questions to both the youth and the parents
- It is important for Scouters to be educated by the parents on the youth's condition so that they understand the youth's unique abilities and challenges
- To support both skill and social development on the part of the youth, an attitude of inclusion must be adopted by both the Scouters and the other youth in the group
- If you don't understand something, ask for it to be explained
- Check that the youth's equipment is comfortable for them to use in every setting
- Establish an on-going rapport with all the support people involved in the youth's life
- The youth may use special equipment such as devices for communicating, orthosis for ankle and feet, crutches for his/her forearms, wheelchairs, electric scooters etc.
- Be aware that youth with CP may pose a higher choking risk

PROGRAM MODIFICATION SUGGESTIONS

- Be aware that the youth may tire quickly
- Youth may experience challenges maintaining the pace of a two way conversation
- Scouters and youth will want to be patient, understanding, and supportive towards the youth
- The youth may require assistance with the carrying of their luggage and other personal belongings
- In relation to physical games, the youth may be unable to compete equally and/or may exhibit varying degrees of instability, depending on the activity
- Flexibility and adapting to allowing all youth participants the option of changing the rules in some games for accommodations must be the norm
- The youth may require an allowance for more time to complete tasks and activities
- Be aware that any sudden excitement, tiredness, loud noises such as a whistle, may lead to the youth becoming startled, with exaggerated reflex reactions; they may subsequently place themselves and others at risk
- Plan for all surfaces and areas to be free from potential hazards
- Accommodations for a Personal Support Worker (PSW) may be necessary for youth who are low functioning, with identified needs

FURTHER ASSISTANCE

This Info Sheet is a resource guide only and is not intended to be therapeutic, diagnostic, medical, or legal advice. Our best source of assistance for youth with identified needs is the youth's parents or caregivers; the information provided is designed to support the relationship that exists between a youth and his/her parents or healthcare providers and the Scouters involved with the youth.

SOURCES

www.nhs.uk/Conditions/Cerebral-palsy/Pages/Symptoms.aspx, and material adapted and used by permission of The Cerebral Palsy Association of British Columbia, The Scout Association (UK), Scouts Australia, and Scouting Ireland

