



CEREBRAL PALSY

Who Owns Your Body?

Young people with physical disabilities may have difficulties learning to take care of themselves. Ask yourself the following:

- Do your parents do things for you because it's faster or easier?
- Do your parents teach you about self-care techniques or about special equipment?
- Do you let others look after you because learning to take care of yourself is hard?

* It may be hard to take care of yourself—but you can do it, and you should do it! Here is what you need to know.

What is Cerebral Palsy?

Cerebral palsy is one of the most common causes of all birth disorders.² Cerebral palsy affects 2 to 2.5 of every 1,000 babies born in developed countries.³ It occurs equally in males and females. Cerebral refers to anything in the head, and palsy is anything wrong with the control of muscles or joints. In most cases the cause of cerebral palsy (CP) is not known. Most people with cerebral palsy have congenital CP, an injury to the nervous system usually occurring before, during, or shortly after birth. Children with the highest risk for developing CP are those born premature, those who are very small and do not cry in the first five minutes after birth, those with seizures in the newborn period, and those with congenital malformations in systems.⁴ CP during infancy and early childhood is most often caused by asphyxia. This injury causes changes in the structure of the brain. Head trauma and infection also can lead to injury. Because of this injury, the brain is not able to tell the muscles in the body to act in the normal way (“palsy”). People who have CP may not be able to walk, talk, eat, or play in the same way as most other people. It is important to know that CP is not a disease or illness. CP is not contagious and doesn't get worse. People who have CP will have it all their lives.

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Special Other Topics of Interest

- A Guide to Driving
- Spina Bifida
- A Guide to Independence

Knowing Your Body:

- Take control of your own life.
- Depend less on your parents.
- Be able to explain your needs to others.
- Know how to keep yourself healthy.
- Be aware of danger signals.
- Make sure you're getting proper medical treatment.
- Know what questions to ask when visiting health professionals.

What Is The Correct Terminology?

In the past there has been a lack of awareness and sensitivity with respect to the words used regarding persons with disabilities. It is important that proper terminology be used to advance awareness of the issues of education, employment, and public access for persons with disabilities.

Words are powerful. A person's self-image is strongly tied to the words used to describe him/her. Using people first language is crucial. People first language puts the person before the disability and it describes what a person has, not what a person is. As young adults with special health care needs, it's often the medical diagnoses or label that can contribute to devaluing and disrespecting you as an individual. The disability label is a passport to services. The only place where the use of disability labels is appropriate or relevant is in the service system and in the medical or legal settings.⁵



Using the correct term is important.

Do you use the correct terms when describing your medical condition?

Mumbo Jumbo Words

Cerebral Palsy (CP) is the term to describe a motor impairment resulting from an injury to the brain before, during, or after birth, regardless of the cause. **Cerebral** means brain. **Palsy** means not using muscles in the normal way.

Disability is the term to define a restriction in the ability to perform normal daily living activities.

Handicapped describes a person who, because of a disability, is unable to achieve the normal, age appropriate role in society.

Impairment is the term to define a change from normal, such as unwanted movement or inability to move a muscle.

Mumbo Jumbo Words

Asphyxia occurs when not enough oxygen reaches the cells.

Ataxic is low muscle tone with poor coordination of movement, shakiness, and tremors.

Athetoid is mixed muscle tone. Muscles are sometimes too tight, and sometimes too loose.

Augmentative Communication Technology (ACT) aids to foster independence communication.

Botox is a botulinum toxin, a protein.

Dysarthia occurs when it is hard to control or coordinate the muscles needed to talk. Speech may sound very slow and slurred.

Intrathecal space is space within a sheath, as in the cerebrospinal fluid within the theca of the spinal canal.

Occupational Therapy focuses on hand function, perceptual motor skills, and other daily living activities.

Physical Therapy develops functional mobility, gait/mobility training, and immediate post operative management.

Spastic is tight muscles with stiff and jerky movements.

Spasticity Clinic provides a multidisciplinary assessment of spasticity.

Spastic Hip Subluxation consists of a dislocation of the leg in the hip socket.



**Know what the
words mean.
Understand
yourself!**

Problems Associated With CP

People with CP may have many problems, not all problems related to brain injury. Yet, most of the problems are neurological in nature. They include epilepsy, mental retardation, learning disabilities, and attention deficit-hyperactivity disorder. Other problems may be hip subluxation, speech, swallowing, and communication problems.

Types of Cerebral Palsy

Spastic Cerebral Palsy

People with spastic CP have stiff and jerky movements in their bodies. This is because their muscle tone is too high, and their muscles are too tight. They often have difficulty moving from one position to another or letting go of something. This is the most common type occurring in about one-half of all people with CP.

Athetoid Cerebral Palsy

People with athetoid CP have mixed muscle tone. Their muscle tone is sometimes too high and sometimes too low. They often have trouble holding themselves in an upright, steady position for sitting or walking. They often show a lot of movement in their upper body and make faces unintentionally. They make large movements, so it may take a lot of concentration to perform a simple task like reaching for a cup. Because of the mixed muscle tone, they may have trouble keeping a position and may not be able to hold onto small items like a pencil or fork. About one-fourth of all people with CP have athetoid CP.

Ataxic Cerebral Palsy

People with ataxic CP look very unsteady and shaky. They have a lot of shakiness, especially when they are trying to do something like write or turn a page. They also often have very poor balance and have a wide-based gait when they walk. Because of this shaky movement they often take longer to perform a task. The ataxic form is the least seen form of CP.

Mixed Cerebral Palsy

- It is common for people to have symptoms of more than one of the previous three forms. This is when muscle tone is too low in some muscles and too high in other muscles, hence the name mixed CP. About one-fourth of all people with CP have mixed CP.

UCP National Facts & Figures www.ucpa.org

What type of cerebral palsy do you have?

Treatments For Spasticity

Currently, oral medication, botox injections, baclofen infusion, orthopedic surgery, selective dorsal rhizotomy (SDR), physical therapy, and braces are used to treat spasticity and related problems.

- **Oral medications**, such as valium and baclofen are used.
- **Botox injections** are injected directly into the affected muscle. The brain sends messages to make the muscles contract or move. These messages are transmitted from the nerve to nerve by a substance called Acetylcholine. When too much Acetylcholine is released, the muscles become overactive and tense up (spasm). Botox blocks the nerve from releasing Acetylcholine. As a result, the muscle spasms are reduced or stop altogether. The effects last about 3 - 4 months, then the muscle has to be injected again.
- **Intrathecal Baclofen** is a muscle relaxant that is administered by a pump. It is different than the Baclofen taken by mouth because the pump delivers the drug (Baclofen) directly to the fluid around the spinal cord. This causes the muscle to relax.
- **Orthopedic operations** include muscle releases and tendon-lengthening procedures. This improves the range of motion in joints. It treats the consequences of spasticity, but does not directly reduce spasticity.
- **Selective Dorsal Rhizotomy (SDR)** involves the cutting of sensory nerve fibers. These rootlets come from the muscle and enter the spinal cord. Abnormal rootlets are selectively cut, leaving the normal rootlets intact. This reduces the messages from the muscles which reduces the spasticity.
- **Physical therapy** helps to prevent the weakening or deterioration of muscles that can follow lack of use and avert contractures (muscles become fixed in a rigid, abnormal position).
- **Bracing** helps compensate for the muscle tone spasticity. Bracing also prevents secondary problems with contractures.
- **Speech and language therapy** aids in improving communication skills. Speech therapists may work on improving talking, pronunciation, using sign language, or using communication aids. The speech problem that most people with CP have is called dysarthria.
- **Acetylcholine** is a substance widely distributed in the body tissues that helps with the transmission of nerve impulses (messages) in the nervous system.

CP symptoms differ from one person to the next and may even change over time in the individual.



Ask questions about your treatment.

Sources for information: Mosby's Medical & Nursing Dictionary

Effects of Spasticity

Spasticity adversely affects muscles and joints, causing abnormal movement. The following are adverse effects:

1. Constrained movement.
2. Lack of muscle growth.
3. Limited stretching of muscles in daily activities.
4. Deformities in the development of muscles and joints.

What Medications Are You Taking?

Most people take medications. It is up to you to:

- Keep track of what pills you take and what they are for,
- Learn how you should take them, and
- Recognize any side effects.



Know your medications.

Medications are powerful tools that help us take care of ourselves and manage our health. They must be treated with respect. Never change the amount or stop taking any medication without first talking to your doctor.

Questions About Your Medications

- What is the name of the medication? Is this the brand or generic name?
- What is the medication supposed to do? How does it affect you?
- How and when do you take it – and for how long?
- What foods, drinks, other medications, or activities should you avoid while taking this medication?
- Could there be a possible reaction between this medication and any other non-prescription, over-the-counter medication you might use?
- What are the possible side effects? What do you do if they occur?
- How and where do you store the medication?
- Do you need to refill the prescription?
- Do you need any lab tests while taking the medication?
- Is there any written information available about the medication?



Ask questions about your medications.

Never change the amount or stop taking any medication without first talking to your doctor.

Establish A Bowel Routine

The key to bowel management is to have a bowel movement at the same time every day, preferably after a meal. Establishing a bowel routine takes time and patience.

A Natural Schedule

You already may have a natural internal schedule. About 20 to 30 minutes after a meal, there is a natural body response to evacuate the bowel.

Watch for a week or two and use your own natural schedule, if possible, when choosing a daily time. After breakfast or supper works for many.

No More Than 2 Days

Never let more than 2 days go by without a bowel movement. The longer the time between bowel movements the harder and drier the stool gets. For some people combining a regular toileting schedule, for example, 5 to 10 minutes at the same time every day, with a high fiber diet of fruits, vegetables, whole grains or bran, and plenty of water is all that is needed.

Special Help

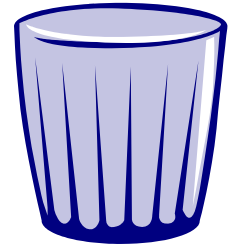
Sometimes a suppository, stool softener, bulk former, or laxative will be needed if your bowel tone is not normal. To empty the bowel completely before any of these can be effective, an enema may be needed. Discuss any use of medication with your doctor.

Between a Bone and a Hard Place

Pressure sores, skin ulcers, bedsores, decubitus, and tissue trauma are all caused by skin pressing or rubbing between the bone and something that is hard. Pressure sores can be caused by your wheelchair, leg brace, or even a fold in your clothing. Because of the pressure there is abnormal blood flow to that area and the skin is starved of oxygen.

Four Stages of Pressure Sores

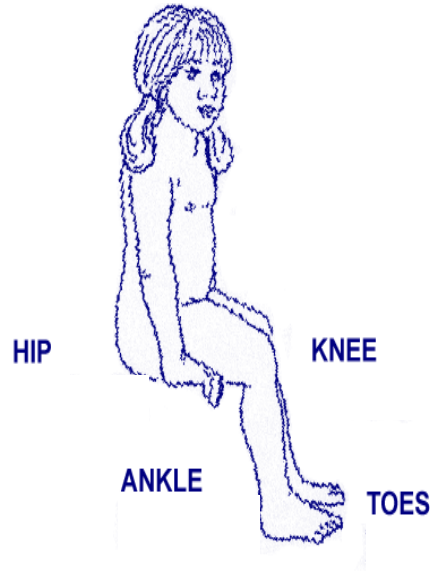
- **Pressure Sore—Decubitus Ulcer— Tissue Trauma**
- In **Stage I**, the skin is red and the color of the skin does not return to normal with relief of pressure.
- In **Stage II**, the skin is blistered, although damage is still superficial.
- In **Stage III**, the skin is broken. A full thickness of skin is lost and bloody drainage may be seen.
- In **Stage IV**, a deep craterlike ulcer has formed. The full thickness of skin and tissues are destroyed. Tissue, bone, or muscle under the ulcer are exposed and may be damaged.



Drink at least 8 glasses of water a day.

The key to bowel management is to have a bowel movement at the same time every day.

Pressure Sores



These are common areas of pressure sores.

Avoid Pressure Sores

→ Check these spots every day with your mirror.

- Elbows
- Hips
- Butt
- Behind knees
- Feet
- Ankles
- Heels

Pressure sores are caused by the lack of normal blood flow to the skin.



The skin is squeezed between bones and something that is hard.



This cuts off the blood supply to the skin.



The skin sends a message to the brain to move.



With cerebral palsy, it is not always possible to move. The blood supply may be cut off, and oxygen and nutrients don't get to the skin -



THE SKIN BEGINS TO DIE!

Did you check for pressure sores today?

Why You Don't Want Pressure Sores

- They take a long time to heal.
- You may need skin grafts - more surgery.
- You may have to spend days - or even weeks - lying on your stomach, and that is VERY BORING!

What Are You Going To Do To Prevent Pressure Sores?

- Recognize where pressure sores are likely to develop.
- Relieve pressure and increase circulation with daily exercise.
- Move and shift positions frequently during the day.
- Change positions with pillows, pads, etc. to relieve pressure.
- Keep your weight healthy.
 - overweight = extra pressure
 - underweight = no padding
- Eat a well balanced diet.
- Check that you have not outgrown your wheelchair, braces, or shoes – review these once a year with a physical therapist.
- Use good transfer techniques to reduce friction.
- Maintain good skin hygiene.
- Keep your skin clean and dry. Wet skin is more likely to get pressure sores, so change pads or wet clothing as soon as possible.
- Use a mirror and check your backside daily.
- Treat any redness early by cushioning the area to relieve the pressure.



Pressure sores may require surgery.

Prevention is easier than repairing and healing from a pressure sore.

The Big Test

1. Who owns your body?
2. Why should you understand cerebral palsy?
3. What type of cerebral palsy do you have?
4. Have you had any surgery?
5. What medications do you take?
6. What are the side effects of your medication?
7. How should your medication be stored?
8. What is a pressure sore?
9. How can you avoid a pressure sore?
10. Are you ready to take charge of your future?

REFERENCES

1. Miller, Bachrach, et al , Cerebral Palsy: A Guide for Care, Hopkins Press.
2. Liptak GS (2001). Cerebral palsy. In RA Hoekelman, ed., Primary Pediatric Care, chap. 38, pp. 468–473. St. Louis: Mosb.
3. Rapp CE, Torres MM (2000). The adult with cerebral palsy. Archives of Family Medicine, 9: 466–472.
4. Pellegrino L (1997). Cerebral palsy. In ML Batshaw, ed., Children With Disabilities, 4th ed., pp. 499–528. Baltimore: Paul H. Brookes Publishing.
5. Snow, Kathie, *People First Language*, www.disabilityisnatural.com.

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SOUTHWEST INSTITUTE
for Families and Children with Special Needs

5111 North Scottsdale Road
Suite 105
Phoenix, Arizona 85250
(480) 222-8800
www.swifamilies.org

Prepared by
Maggy Haugen, RN, BSN,
Care Coordinator

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**Children's Rehabilitative
Services**
124 W. Thomas Rd.
Phoenix, AZ 85013

Ginger Coleman RN, BSN
Phone:
(602) 406-6412

Email:
gcolema@chw.edu