FACT SHEET

American Academy
for Cerebral Palsy and
Developmental Medicine

Care of Adults with Cerebral Palsy

As a PCP, you play an important role in the care of an adult with cerebral palsy. Although you may have had limited exposure to patients with CP in the past, most of their primary care needs are similar to those of other adults. Many adults with CP are able to work, attend college and have a successful careers and families. There are specifics about CP that will help you provide optimal care.

CP is "a group of permanent disorders of the development of movement and posture, causing activity limitations, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain"[1]. CP refers *only* to motor disability. However, CP is commonly associated with other developmental problems: intellectual disability, epilepsy, visual or hearing impairments, and behavioral problems.

Common causes of CP include prematurity, perinatal infections, genetic syndromes, brain malformations, and anoxic or traumatic injuries. Frequently, the cause of CP is not known.

Due to improved care during childhood, most patients with CP are likely to live to adulthood. For instance, a 15 year old girl with CP who can walk without assistance has a *median* survival of 55 additional years. Life expectancy decreases with increasing need for assistance from others[2]. A Physiatrist (Rehabilitation Medicine Physician) may help your team preserve nerve, muscle and bone function in patients with high mobility concerns.

Several conditions are directly related to the motor disabilities of CP. With a lifetime of abnormal forces on the joints, there is a high prevalence of osteoarthritis. Because of activity limitations, osteoporosis is very common, and at early ages[3]. These may be treated with standard therapies.

The Conditions *associated* with CP often lead to medical problems which require follow-up and treatment[4]:

- Epilepsy (with long-term side effects of treatment)
- Hearing or visual loss, which may be progressive
- Respiratory Insufficiency (especially with prematurity or scoliosis)
- Hypertension (especially with prematurity)
- Nutritional problems, including under-weight and over-weight
- Kidney stones

- Fatigue and depression

Specific primary care priorities for adults with CP include[5]:

- Anticipatory guidance (includes advanced care planning, supported living or guardianship for some)
- Care Coordination
- Immunizations
- Discussions of age-appropriate cancer screening (includes risks, benefits, and practical considerations)
- Dental care

There are "Red Flags" in the care of adults with CP. The neurologic injury that caused CP does not change, but there can be progressive impairments. These are *not* inevitable and should be investigated thoroughly.

☑**Loss of previously attained skills** may indicate new neurologic impairment, which could be caused by spinal problems, including disc disease or spinal stenosis-see the fact sheet (hyperlink). It is vital to have a complete baseline neurological exam on each patient so that changes can be detected.

☑**Changes in behavior**, particularly among adults with cognitive difficulty, should be investigated as a symptom of a medical problem before being ascribed to "behavior". Common causes of changed behavior include:

- Pain
- Medication interactions or side effects
- Seizures
- Change in environment (including abuse)
- Psychiatric disease should be considered only after other causes have been ruled out.

Many people with CP have spastic muscles which do not affect the sexual organs directly. Both men and women can look forward to a full and active sexual life. Sex can be enjoyed if the person is willing to learn to have sexual pleasure in different ways with different techniques and positions. It may take practice for individuals with CP to find ways to enjoy sex (spasms can even enhance the experience). Initiate a discussion on contraception and sexually transmitted disease prevention, especially with young adults. As survival rates are increasing for young adults with special health care needs, consider "quality of life" as you make decisions with your patients about the future. A person-centered approach, beyond medical needs alone is helpful to achieve this goal.

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This fact sheet was created by the Lifespan Committee of the American Academy for Cerebral Palsy and Developmental Medicine. More resources can be found at www.aacpdm.org

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2. Strauss D, Brooks J, Rosenbloom L, Shavelle R. Life expectancy in cerebral palsy: an update. Dev Med Child Neurol 2008;50:487-93.
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