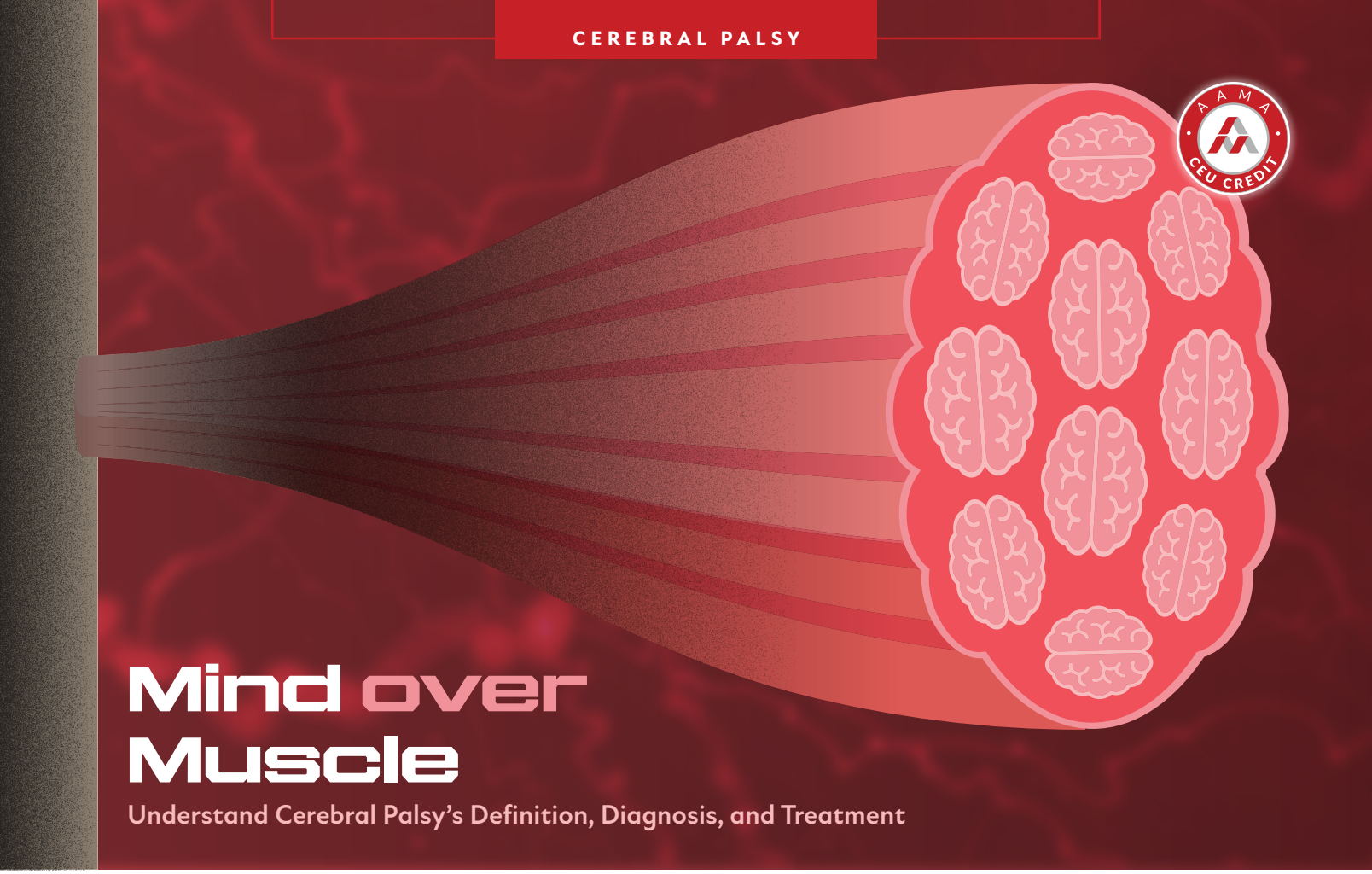

Mind over Muscle

Understand Cerebral Palsy's Definition, Diagnosis, and Treatment

By Pamela Schumacher, MS, Prosci, RYT

Cerebral palsy (CP) is a lifelong neurological condition that affects movement, muscle coordination, and posture. Caused by abnormal brain development or damage to the developing brain before, during, or shortly after birth, CP is the leading cause of childhood disabilities in the United States. It affects individuals in different ways and to varying degrees—someone with mild CP may not need any assistance or may have slight problems, while a person with severe CP might need special equipment and lifelong care.[1]

"Medical assistants interact with patients with cerebral palsy at nearly every point in [a health care] journey—from rooming appointments and taking vitals to scheduling, prior authorizations, and patient education," says Elaine Lin, MD, codirector of the Cerebral Palsy and Spasticity Center at Boston Children's Hospital in Boston, Massachusetts. "It's important to recognize that there are so many little things that can help a family feel supported, no matter how complicated or complex the situation may be. Families want to be heard, respected, and listened to, and even if you don't have all the solutions, it's OK."

CP Defined

"Cerebral palsy is not a disease. It is a condition that results from some type of injury to the developing brain that leads to difficulty with movement and coordination," says Laurie Glader, MD, section chief of complex care and medical director of the Cerebral Palsy Program at Nationwide Children's Hospital in Columbus, Ohio.

"CP has a wide range of ways in which it manifests," she says. "Some children can run and climb, with minimally visible challenges in balance and coordination. Others may be more affected and need a wheelchair pushed by someone else to get around. CP is different for everyone, and there are different types of CP. Also, CP is not just a childhood condition. It is lifelong and affects even more adults than children."

Physicians classify CP according to the main type of movement disorder involved. Depending on which areas of the brain are affected, one or more of these movement disorders can occur[1]:

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

"It's important to understand that no two patients with CP are identical," says Dr. Lin. "Also, unlike other neuromuscular disorders, CP is not progressive—the brain lesion does not change. However, the functional consequences of CP—pain, contractures, and spasticity—can get worse with time. CP is defined as a motor impairment, and while intellectual disability is common, it is not a defining feature."

"A lot of people think of CP as something that went wrong during birth—something that the ob-gyn did wrong. We now understand that's very rarely the case," says Eric Chin, MD, assistant professor of neurology, neurological surgery, and pediatrics at Kennedy Krieger Institute in Baltimore,

Maryland. "Most often, causes like premature birth, a stroke, or genetic differences aren't easily preventable. That means there's nothing that the parents, the ob-gyn, or the pediatric team did wrong."

Risk Factors, Signs, and Symptoms

Certain events and medical conditions during pregnancy may increase the risk of cerebral palsy. These factors can affect the developing brain before birth and may contribute to complications associated with CP. Common risk factors include the following[2]:

- Low birth weight or preterm birth
- Multiple gestations
- Infertility treatments
- Infections during pregnancy
- Fever during pregnancy
- Unmatched blood factor between the mother and fetus
- Maternal medical conditions (e.g., abnormal thyroid function, intellectual and developmental disability, too much protein in the urine, and seizures)
- Complicated labor and delivery
- Jaundice
- Seizures

Symptoms of CP can differ widely depending on the type and severity of the condition. One of the earliest signs may be delays in reaching developmental movement milestones, such as rolling over, crawling, or standing.[1]

"Medical assistants often notice developmental concerns during intake. Early signs to look for include the infant not meeting milestones like sitting or walking, favoring one side of the body, persistent muscle stiffness or floppiness, and difficulty feeding," says Shannon Richardson, CMA (AAMA), supervisor at Klickitat Valley Family Medicine in Goldendale, Washington. "Accurate documentation by the medical assistant of milestones, caregiver concerns, and observations can prompt further evaluation."

Diagnosis

To diagnose CP, a physician will order a series of tests to evaluate the child's motor skills. During visits, the physician will monitor development, growth, muscle tone, motor control, hearing and vision, posture, and coordination. An ultrasound or MRI may be used to show the location and type of damage.[3]

"There may be signs of developmental delay and abnormal tone, so Early Intervention, a federally mandated program that can provide physical, occupational, and speech therapy to infants from birth to age 3, is critical during this time," says Dr. Lin.

Once a diagnosis is made, the mobility and gross motor skills of people with CP are categorized into levels I–V, using the Gross Motor Function Classification System (GMFCS). The levels are based on functional limitations, the need for hand-held mobility devices (such as walkers, crutches, or canes) or wheeled mobility, and quality of movement.[4]

The GMFCS levels are[4]:

- Level I: A child can walk and climb stairs without using hands for support, as well as run and jump. They have decreased speed, balance, and coordination.
- Level II: A child can walk and climb stairs using a railing and can minimally run or jump. They will have difficulty with uneven surfaces, inclines, or while in crowds.
- Level III: A child can walk with assistive mobility devices on level surfaces and may be able to climb stairs using a railing. They may propel a manual wheelchair, but may require assistance for long distances or uneven surfaces.
- Level IV: A child's walking ability is severely limited, even with assistive devices. They use a wheelchair most of the time and may propel their own power wheelchair. They may participate in standing transfers.
- Level V: A child has physical impairments that restrict voluntary movement control and the ability to maintain head and neck position against gravity. They experience impairment in all areas of motor function and cannot sit or stand independently, even with adaptive equipment. They cannot independently walk, though may be able to use powered mobility devices.

"Generally, a child over the age of 5 won't improve their GMFCS level. For example, if a child is classified at a Level IV when they're 6, then it's likely that they'll need to use a mobility device throughout their lifetime," says Dr. Lin.

Treatment

Although CP cannot be cured, early inter-

Types of Cerebral Palsy

Cerebral palsy presents in several main types[1]:

- **Spastic CP** affects about 80% of people with CP. People with spastic CP have increased muscle tone, meaning their muscles are stiff and their movements can be awkward.
- **Dyskinetic CP** causes problems with controlling the movement of one's hands, arms, feet, and legs. Sometimes the face and tongue are affected. Movements are uncontrollable and can be slow and writhing or rapid and jerky. Muscle tone can change (varying from too tight to too loose) not only from day to day, but even during a single day.
- **Ataxic CP** causes problems with balance and coordination. People might be unsteady when they walk or have a hard time with quick movements or movements that need a lot of control, like writing.
- **Mixed CP** involves symptoms of more than one type of CP. The most common type of mixed CP is spastic-dyskinetic CP.

vention and ongoing treatment can help improve a child's movement, communication, and daily functioning. A multidisciplinary care plan will be created, typically including referrals to pediatric neurology, physiatry (rehabilitation medicine), physical and occupational therapy, speech-language therapy, and sometimes nutrition and orthopedics.[3]

"A typical lifetime journey for a patient with CP would include early intervention with physical, occupational, and speech therapy," says Dr. Lin. "With school-age children, we focus on maximizing functional independence, educational inclusion, managing tone—with medications or surgeries, and minimizing pain. In adolescence, puberty may make spasticity or seizures worse, and the recommendation is for transition to adult care discussion to start by age 14. As comorbid conditions arise or as the level of disability becomes more apparent, optimizing function and comfort should be considered at all stages."

CP is frequently accompanied by comorbidities that affect multiple bodily systems, with some of the most common being intellectual disability (48% of cases), epilepsy (42%), and speech/language disorders. Other common co-occurring conditions include visual impairments, feeding difficulties, and gastroesophageal reflux disease.[5]

"Comorbid conditions are all due to the primary brain lesion affecting motor pathways and subsequently other interconnected areas of the brain," says Dr. Lin. "Some patients with CP may have technology dependence—e.g., gastrostomy tube, tracheostomy, etc.—due to these comorbidities. To properly address the comorbid conditions, clinicians should have a systematic approach and provide anticipatory guidance to families."

Dr. Lin suggests looking for the following:

- **Seizures.** Any concerning movements or behaviors should be assessed for possible seizure activity and referred to neurology for evaluation and possible medication.
- **Nutrition and feeding issues.** There are CP-specific growth curves that should be reviewed in addition to Centers for Disease Control and Prevention and World Health Organization growth curves. Difficulty swallowing can cause aspiration, and patients should be referred for feeding and swallowing assistance.
- **Constipation**. Monitoring bowel movement frequency and consistency is important, as well as intervening with dietary changes and medication. Referral to gastroenterology may be required to help with motility or feeding intolerance issues.
- **Orthopedic complications.** Hip and spine screening is recommended at certain intervals based on functional classification (I–V); the American Academy of Cerebral Palsy and Developmental Medicine has good guidance on this.
- **Pain.** Pain can come from one or several sources and can be very hard to differentiate when the patient is nonverbal. Process of elimination can help determine the source of pain.
- **Drooling.** Drooling is seen in up to one-third of patients with CP and may be due to gastroesophageal reflux, dysphagia, or medication side effects. Drooling is a problem when hygiene becomes challenging or when difficulty swallowing occurs. There are medications and possibly surgical interventions (e.g., salivary Botox, salivary gland excision).
- **Mental health and behavior.** Depression and anxiety are not uncommon, and a referral to psychiatry or behavioral health team may be needed for management.
- **Vision and hearing.** Screening may need to be performed by a specialist and should be done routinely for patients throughout childhood. A referral to audiology and ophthalmology may be necessary for management.

"Remember, during any assessment, it could be painful to move a spastic limb. Just doing a blood pressure check could hurt," says Christina Marciniak, MD, professor of physical medicine and rehabilitation and neurology at the Northwestern University Feinberg School of Medicine in Chicago, Illinois. "Some patients with CP have terrible tone in their elbow flexors or another limb. In addition, people can have asymmetries, and one side works differently than the other. Ask the patient what works best for them."

Symptoms

The Institute of Neurological Disorders and Stroke lists common symptoms of CP[3]:

- Ataxia
- Delays in reaching movement milestones
- Difficulty with fine motor skills
- Dystonia
- Epilepsy
- Growth and development delays
- Hearing and vision issues
- Incontinence
- Intellectual or learning difficulties
- Osteoarthritis
- Problems with the spine
- Spasticity
- Speech and language challenges
- Stiff or floppy muscle tone
- Unusual gait
- Weakness in one or more arm or leg

Growing Up and Out of the System

Today, more adults than children are living with CP in the United States. Advances in medical care and early interventions have increased life expectancy, allowing many individuals with CP to live long and active lives into adulthood. And yet, many adult patients have difficulty maintaining consistent medical care.[6]

"The transition from pediatric to adult care is challenging—the biggest issue is that there are no equivalent adult CP centers where patients can get multidisciplinary care," says

Dr. Lin. "Care becomes fragmented across neurology, physiatry, orthopedics, and primary care. In pediatrics, there is often a strong medical home overseen by the primary care physician or a care coordinator who helps families navigate the health care system as well as their educational and home services. The transition away from school into vocational or day programs is very challenging, and the lack of school-based therapy is a huge loss for families. The transition in insurance coverage can also disrupt therapies, equipment, medical supplies, and home care services."

"Adults with CP face all the things we face as adults, including cardiovascular problems, obesity, and hypertension, … along with the impairments they may have had since childhood," says Dr. Marciniak. "However, they may have new issues sooner. For instance, in people with severely limited mobility in childhood, osteoporosis can be seen much earlier in adulthood because their bone development is impaired, the bones are less dense from inactivity, and some antiseizure medications worsen bone health. Patients with severe osteoporosis are more likely to have fractures, and this can occur with even typical activities, such as a transfer. Further, progression in common impairments such as contractures, spasticity, pain, and arthritis may lead to an earlier loss of function, such as ambulation abilities. Also, as they get older, you should assume patients with appropriate cognitive abilities with CP, even with severe motor impairments, may be sexually active. Women should be offered regular gynecologic care."

Throughout their care and treatment, don't forget to approach each patient as an individual, reminds Dr. Glader: "There can be a misconception that just because a person has difficulty controlling their body, they do not lead a fulfilling life. This is a myth! With therapies and support, most people with CP thrive. Many people with CP can live independently, drive cars, and have families and a career." ✦

Medical Assistant Checklist

Communication and Interaction

- Engage directly: Speak to the patient, not just their caregiver. Often, people with CP hear and understand more easily than they can communicate back.
- Use augmentative and alternative communication devices: Be familiar with or facilitate the use of tools, such as communication boards or speech-generating devices.
- Avoid assumptions: Do not assume all patients with CP have cognitive issues.
- Be patient: Allow extra time for responses.

Scheduling and Environment

- Flexible scheduling: Offer longer, earlier, or later appointments to accommodate transportation issues and reduce anxiety.
- Accessibility: Ensure walkways are clear and that there is step-free access to the building and examination rooms.
- Create a comfortable environment: Adjust lighting, reduce noise, and offer supportive seating to minimize sensory distress and muscle spasticity.

Clinical and Practical Support

- Positioning and safety: Assist with safe transfers and ensure proper positioning in the examination room to prevent skin breakdown or discomfort.
- Medication and therapy coordination: Assist with, or provide reminders for, scheduling specialized treatments, including Botox injections, orthopedic assessments, and physical therapy.
- Pain management: Actively inquire about pain levels.

Transitioning to Adult Care

- Support specialized care: Assist with transitioning from pediatric to adult care by coordinating with specialized clinics.
- Advocate: Speak up for accommodations, ensure patient concerns are heard, and promote inclusive care practices.
- Consider screenings: As they transition to adulthood, patients may need screenings such as DEXA scans, cholesterol tests, or gynecologic care.

The CE test for this article can be found on page 27.

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