



## Caring for patients with cerebral palsy: Report highlights key guidance for pediatricians

November 21, 2022

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Article type: [AAP Clinical Report](#)

Topics: [Disabilities](#)

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Are these scenarios common in your practice?

*A 9-month-old full-term baby is unable to sit independently. When suspended, he scissors his legs. How should he be evaluated and treated?*

*A 5-year-old girl with cerebral palsy presents for her prekindergarten physical. How can you help the child get medically and educationally necessary services?*

*A 12-year-old boy with cerebral palsy has progressive scoliosis. The family asks you to help them decide whether he should have spinal fusion.*

*An 18-year-old woman with cerebral palsy is finishing high school. How can you help her navigate the transition to college and adult care?*

An updated AAP clinical report emphasizes the vital role that primary care pediatricians (PCPs) play in the detection and management of children with cerebral palsy (CP), the most common motor disorder of childhood.

The report *Providing a Primary Care Medical Home for Children and Youth with Cerebral Palsy* and an executive summary provide pediatricians with guidance to detect CP in children; collaborate with specialists; manage the associated medical, developmental and behavioral problems; and provide general medical care to patients.

The documents, from the AAP Council on Children with Disabilities and the American Academy for Cerebral Palsy and Developmental Medicine, are available at <https://doi.org/10.1542/peds.2022-060055> and <https://doi.org/10.1542/peds.2022-060056> and will be published in the December issue of *Pediatrics*.

### **Characteristics, risk factors, signs**

Cerebral palsy describes “a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to nonprogressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior, by epilepsy, and by secondary musculoskeletal problems” (Rosenbaum P, et al. *Dev Med Child Neurol Suppl.* 2007;109:8-14).

Children with CP may have increased tone, low tone or movement disorders. There is a breadth of severity. Some children can walk without assistance, some require assistive devices and others use wheelchairs full time.

PCPs need to be alert to the possibility of CP in children with known risk factors, such as prematurity or perinatal difficulties, as well as in those with unremarkable birth histories. Signs that may indicate CP include motor asymmetry such as early hand preference (not seen in typically developing children until age 18 months); “thumb-in-fist” posture beyond 7 months; inability to sit independently by 9 months; and altered muscle tone, such as scissoring of the legs.

The clinical report recommends the PCP take three actions simultaneously when a child is identified as having a possible neuromotor disorder:

- Initiate a diagnostic workup based on the suspected disorder.
- Refer to a medical specialist to complete the diagnostic evaluation.
- Refer to early intervention programs and therapists for treatment. Early identification and initiation of evidence-based motor therapies can improve outcomes by taking advantage of the neuroplasticity in the infant brain.

### **Managing medical needs**

A key role of the PCP is to integrate care across multiple specialists so that all of the child’s needs are addressed, including cognitive and learning problems, behavioral symptoms, pulmonary and gastrointestinal symptoms, and orthopedic issues.

Pain and fatigue also are common. Challenging behaviors may be a means of expressing physical discomfort, fatigue related to poor sleep or distress related to a change in routine in those with limited verbal skills. The PCP plays an important role in assessing for sources of physical discomfort.

### **Easing transition to adult care**

As with other children with chronic illnesses, late adolescence and early adulthood is a vulnerable time for those with CP. If proper preparation and handoffs to adult physicians do not occur, there is an increased risk of medical complications and unnecessary emergency department visits, hospitalizations and procedures.

Studies show young adults with CP do not feel well-prepared for this transition. Therefore, PCPs should start the transition early using a structured process.

### **Complexity, high cost of care**

The care of children with CP can be extremely complex and costly, both for the family and medical providers. Children and families may be eligible for a range of services that are difficult to access. Payment to physicians for providing expert, coordinated care for children in the medical home often is inadequate. The breadth of the pediatrician's care, as illustrated in the clinical report, is difficult to sustain solely through payment for intermittent office visits.

The AAP is advocating for systemic change to help children with CP, their families and their medical homes.

*Drs. Noritz, Davidson and Steingass are lead authors of the clinical report and the executive summary. Dr. Noritz is chair of the AAP Council on Children with Disabilities Executive Committee. Drs. Davidson and Steingass are members of the council.*

## **Resources**

- The clinical report's executive summary at <https://doi.org/10.1542/peds.2022-060056> highlights 12 points for pediatricians caring for children with cerebral palsy.
- [Early Detection of CP Care Pathway from the American Academy for Cerebral Palsy and Developmental Medicine](#)
- [Information for parents from HealthyChildren.org on cerebral palsy](#)