

Guidelines for the Care of Children and Adolescents with Cerebral Palsy

Basic Team

The special care needs of children with cerebral palsy are best met by an experienced, coordinated team of pediatric specialists working collaboratively with parents, the primary care physician, and other service providers. Not all members of the basic team may be needed at each visit, and other professionals may be required. These include but are not limited to a child neurologist, a neurosurgeon, an ophthalmologist, a nutritionist, a feeding specialist, and a psychologist. Parents of children with cerebral palsy or people with cerebral palsy should be encouraged to participate actively as part of the team. Please note that though a coordinated team is needed to manage the range of specialty services required, all children require a medical home. The primary care physician is responsible for preventive and acute illness care and for coordinating special services.

Regular members of the child development team include a developmental pediatrician or psychiatrist, a medical social worker, a nurse, an orthopedist, an orthotist, physical and occupational therapists, and a speech-language pathologist.

Initial Evaluation

The initial evaluation should be performed as soon as a diagnosis of cerebral palsy is suspected. The following components are recommended: family, medical, and developmental histories; developmental and behavioral assessments; a physical examination, including neuromotor and musculoskeletal assessments; and other tests as indicated. Other tests may include X rays and laboratory tests, a hearing and vision evaluation, an educational evaluation, an assessment of the child's communication skills and needs, and a nutrition and feeding evaluation. An initial management plan that is inclusive of all needed services should be developed.

Frequency of Visits

As the child with cerebral palsy grows and develops, additional needs may become evident that require further evaluation or treatment. In general, the primary care physician should review the child's progress and update the office management plan at least yearly and more often for young children and in the first 2 years of treatment. Children with cerebral palsy also require regular follow-up by the team of specialists. Clear and regular communication among service providers is critical. The child should be reevaluated by the neurodevelopmental team several times per year in the first 2–3 years, twice annually until the child reaches 5 years of age, and at least annually thereafter.

Guidelines for the Care of Children and Adolescents with Cerebral Palsy

The following elements are recommended by age group, and the listing is cumulative. Review all items indicated up through the actual age group of a child entering your practice for the first time as part of the initial evaluation.

AGE	KEY CLINICAL ISSUES/CONCERNS	EVALUATIONS/KEY PROCEDURES	SPECIALISTS
Birth–3 years (infants and toddlers)	<p><i>Growth/Nutrition/Feeding</i> Slow weight gain or linear growth Failure to thrive Oral motor dysfunction Gastroesophageal reflux (GER) Gastrostomy care</p>	<p>Growth parameters, diet record, nutrition and feeding assessment, evaluation of GER (pH study), modified barium swallow as needed Special diet or feeding program, medication (acid blocker and/or motility agent) or fundoplication for GER Gastrostomy as needed</p>	<p>Nutritionist, feeding specialist or team, pediatric gastroenterologist as needed</p>
	<p><i>Associated Medical Problems</i> Hearing and vision Seizures Chronic respiratory problems/aspiration</p>	<p>Hearing and vision testing Electroencephalogram Chest X ray, workup for GER and swallowing dysfunction Diet, cleanout for impaction, medication (bulk agents) Regular stretching, warm bath and massage, ibuprofen, diazepam (rarely) Behavioral management, occasionally short-term medications</p>	<p>Audiologist, ophthalmologist Child neurologist as needed Pediatric gastroenterologist as needed</p>
	<p>Constipation Muscle cramps Sleep problems Drooling</p>	<p>Diet, cleanout for impaction, medication (bulk agents) Regular stretching, warm bath and massage, ibuprofen, diazepam (rarely) Behavioral management, occasionally short-term medications Behavioral therapy, occasionally medications</p>	<p>Developmental pediatrician (DPed), nurse specialist as needed Speech-language pathologist as needed</p>
	<p>Note side effects of any medications.</p>		
	<p><i>Cause of the Disability</i></p>	<p>Evaluation for minor anomalies Cranial magnetic resonance imaging (MRI) or computed tomography (CT) scan, other testing as needed</p>	<p>DPed, medical geneticist as needed</p>
	<p><i>Dental Care</i> Caries Malocclusion</p>	<p>Review oral hygiene</p>	<p>Dentist</p>
	<p><i>Ambulation and Mobility</i> Need for physical therapy (PT) services Need for bracing and adaptive equipment</p>	<p>Detailed neuromotor and musculoskeletal examinations</p>	<p>Physical therapist, DPed, orthopedist, orthotist as needed</p>
	<p><i>Seating and Positioning</i> Need for specialized seating device</p>	<p>Detailed neuromotor and musculoskeletal examinations</p>	<p>Physical therapist, occupational therapist, physiatrist, equipment vendor as needed</p>

Guidelines for the Care of Children and Adolescents with Cerebral Palsy *(continued)*

The following elements are recommended by age group, and the listing is cumulative. Review all items indicated up through the actual age group of a child entering your practice for the first time as part of the initial evaluation.

AGE	KEY CLINICAL ISSUES/CONCERNS	EVALUATIONS/KEY PROCEDURES	SPECIALISTS
Birth–3 years (infants and toddlers) <i>(continued)</i>	<p><i>Upper-Extremity Function and Visual Motor Skills</i></p> <ul style="list-style-type: none"> Need for occupational therapy services Fine motor/visual motor skills <p><i>Musculoskeletal Problems</i></p> <ul style="list-style-type: none"> Joint contractures Hip subluxation or dislocation Scoliosis Foot and ankle deformities Arm and hand deformities Rotational deformities of the legs Osteopenia and fractures 	<p>Detailed musculoskeletal examination, assessment of fine motor and visual motor skills</p> <p>Detailed musculoskeletal examination, hip X rays at age 2 years or before, back and other X rays as needed</p>	Occupational therapist, DPed, orthopedist as needed Physical therapist, occupational therapist, DPed; orthopedist as needed and at least yearly after 3 years of age
	<p><i>Communication, Developmental Progress, Early Intervention (EI) Services</i></p> <ul style="list-style-type: none"> Need for EI services Language delay or speech disorder Developmental delay 	<p>Developmental surveillance</p> <p>Referral for eligibility testing for EI services as needed</p>	Referral to child development team, speech-language pathologist, or psychologist as needed
	<p><i>Review of Diagnosis and Anticipatory Guidance</i></p> <ul style="list-style-type: none"> Information on diagnosis and management Review the individualized family service plan (IFSP) with family as needed Transition from EI to early childhood special education (ECSE) or to community preschool participation Promote self-care and independence 	<p>Family interview, provide educational materials and resource information, initiate care notebook</p> <p>Teacher interview, school conference as needed</p>	Primary care office in collaboration with the neurodevelopmental team
	<p><i>Family Support Services</i></p> <ul style="list-style-type: none"> Respite Parent groups Community health nurse Advocacy (e.g., United Cerebral Palsy Association) Financial services (Supplemental Security Income [SSI]) Other enabling services 	<p>Family interview, parent questionnaires (e.g., Family Needs Survey), provide resource information</p> <p>Service coordination, referral to community services as needed</p>	Medical social worker, referral to community health nurse as needed

Guidelines for the Care of Children and Adolescents with Cerebral Palsy *(continued)*

The following elements are recommended by age group, and the listing is cumulative. Review all items indicated up through the actual age group of a child entering your practice for the first time as part of the initial evaluation.

AGE	KEY CLINICAL ISSUES/CONCERNS	EVALUATIONS/KEY PROCEDURES	SPECIALISTS
Birth–3 years (infants and toddlers) <i>(continued)</i>	<p>Collaboration with Community Services</p> <p>Early intervention</p> <p>Community health nurse</p> <p>Other community providers</p>	<p>Comprehensive service coordination with regular exchange of written information (at least yearly) with other service providers, care conference as needed</p>	<p>Primary care office in collaboration with neurodevelopmental team</p>
3–5 years (pre-school age)	<p>Review of Medical or Surgical Treatment Approaches for Hypertonicity</p> <p>Need for Special Technology</p> <p>Power-drive wheelchair</p> <p>Augmentative and alternative communication (AAC)</p> <p>Computer use for written work</p>	<p>Detailed musculoskeletal and neuromotor examinations, gait analysis as needed</p> <p>Assessment of language and cognitive skills, evaluation of fine motor dexterity and speed</p> <p>AAC clinic, power-drive wheelchair assessment</p> <p>Assessment of visual acuity as needed</p>	<p>DPed, orthopedist, physical therapist, occupational therapist, neurosurgeon as needed</p> <p>Physical therapist, occupational therapist, speech-language pathologist, psychologist, ophthalmologist as needed</p>
	<p>Developmental Progress, Early Childhood Special Education (ECSE) Services</p>	<p>Developmental surveillance, referral for eligibility testing for ECSE as needed</p> <p>Intellectual or educational evaluation, assessment of visual perceptual and visual motor skills as needed and prior to kindergarten entry</p>	<p>Psychologist, speech-language pathologist, or referral to child development team as needed</p> <p>Collaborate with preschool or grade school staff</p>
	<p>Self-Care/Independence</p>	<p>Evaluation of functional skills (PEDI or WeeFIM)</p>	<p>Physical therapist and occupational therapist (family and all professionals)</p>
	<p>Toilet Training/Constipation/Urinary Incontinence</p>	<p>Treat constipation first; use adaptive seating as needed and refer for voiding cystourethrogram (VCUG) and urodynamics as needed</p>	<p>DPed, nurse specialist, urologist as needed</p>
	<p>Dropoling</p>	<p>Oral motor therapy (birth–3 years), other behavioral therapies, medication, and (rarely) surgery (older school-age child)</p>	<p>DPed, nurse specialist, speech-language pathologist as needed, rarely otolaryngologist (ENT)</p>
	<p>Anticipatory Guidance</p> <p>Treatment of hypertonicity</p> <p>Transition to grade school</p> <p>Review IFSP or individualized education program (IEP) with the family</p>	<p>Family and teacher interviews, school conference as needed</p>	<p>Primary care office in collaboration with neurodevelopmental team</p>

Guidelines for the Care of Children and Adolescents with Cerebral Palsy (continued)

The following elements are recommended by age group, and the listing is cumulative. Review all items indicated up through the actual age group of a child entering your practice for the first time as part of the initial evaluation.

AGE	KEY CLINICAL ISSUES/CONCERNS	EVALUATIONS/KEY PROCEDURES	SPECIALISTS
6–12 years (school-age)	<p><i>Associated Learning/Behavior Problems</i></p> <ul style="list-style-type: none"> Learning disability Mental retardation Attention-deficit/hyperactivity disorder (ADHD) <p><i>Reassess Need for Physical and Occupational Therapy Services</i></p> <p><i>Patient Education Regarding Diagnosis and Treatment</i></p> <p><i>Social Skills</i></p> <ul style="list-style-type: none"> Promote social competence Involvement in peer group activities at school and in the community (determine which supports are needed) <p><i>Anticipatory Guidance</i></p> <ul style="list-style-type: none"> Discuss diagnosis and management with child Promote self-care and independence Recreation and leisure activities Review IEP with family Transition to middle school 	<ul style="list-style-type: none"> Behavior checklists, school progress report, review IEP Intellectual and achievement testing as needed <p>Assessment of fine and gross motor and functional skills</p> <p>Patient educational materials</p> <p>Social skills program at school as needed</p> <p>Service coordination, referral to community resources, mentor program</p> <p>Referral to community services; provide educational materials; conduct family and teacher interviews, school conference as needed</p>	<ul style="list-style-type: none"> DPed, psychologist, speech-language pathologist or referral to child development team as needed Collaborate with school staff <p>Physical therapist, occupational therapist, DPed, orthopedist as needed</p> <p>DPed, nurse specialist, physical therapist, and occupational therapist</p> <p>Physical therapist, occupational therapist, psychologist, adaptive physical education specialist as needed</p> <p>Collaborate with school staff</p> <p>Primary care office in collaboration with neurodevelopmental team</p> <p>Referral to physical therapist, occupational therapist, adaptive physical education specialist as needed</p> <p>Physical therapist, occupational therapist, psychiatrist, psychologist, ophthalmologist as needed</p> <p>Physical therapist, occupational therapist, psychologist, medical social worker, vocational specialist as needed</p>
13–21 years (adolescent and young adult)	<p><i>Community Mobility and Driver Training</i></p> <p><i>Self-Care/Independent Living</i></p> <ul style="list-style-type: none"> Determine which supports are needed 	<p>Driver training assessment; assessment of cognitive skills, visual acuity, and visual fields as needed</p> <p>Outpatient physical therapy (PT) and occupational therapy (OT) services as needed; consider inpatient rehabilitation evaluation</p> <p>Independent living skills program, social skills training as needed</p>	

Guidelines for the Care of Children and Adolescents with Cerebral Palsy (continued)

The following elements are recommended by age group, and the listing is cumulative. Review all items indicated up through the actual age group of a child entering your practice for the first time as part of the initial evaluation.

AGE	KEY CLINICAL ISSUES/CONCERNS	EVALUATIONS/KEY PROCEDURES	SPECIALISTS
13–21 years (adolescent and young adult) (continued)	<p><i>Anticipatory Guidance</i></p> <ul style="list-style-type: none"> Promote healthy behaviors (exercise program, weight control, muscle-stretching program) Sexuality and birth control High-risk behavior Career planning and higher education Social isolation Transition to adult medical services 	<ul style="list-style-type: none"> Patient educational materials Gynecologic examination for sexually active women Adolescent, family, and teacher interviews; school conference as needed Career counseling, evaluation by vocational specialist as needed Encourage involvement in after-school and community activities, mentor programs 	<ul style="list-style-type: none"> Primary care office in collaboration with neurodevelopmental team Referral to gynecologist as needed Referral to Department of Vocational Rehabilitation, mental health professional as needed

Family and Physician Management Plan Summary for Children and Adolescents with Cerebral Palsy

The Management Plan Summary should be completed at each annual review and more often as needed. It is intended to be used with the Guidelines for Care, which provide a more complete listing of clinical issues at different ages and recommended evaluations and treatments.

Child's name _____ Person completing form _____ Today's date _____

Clinical issues	Currently a problem?	Evaluations needed	Treatment recommendations	Referrals made	Date for status check
<i>Family's Questions</i> <i>Growth/Nutrition/Feeding</i> Feeding problems Slow weight gain, linear growth Questions about specialized feeding, gastrostomy care					
<i>Associated Medical Problems</i> Recurrent respiratory problems or aspiration Gastroesophageal reflux (GER) Seizures Toilet training (assess need for adaptive seating) Constipation, urinary incontinence Drooling Muscle cramps Hearing loss Strabismus/visual problems Sleep disorder, sleep apnea Note any side effects of medications.					
<i>Cause of the Disability</i>					

Family and Physician Management Plan Summary for Children and Adolescents with Cerebral Palsy (continued)

Child's name _____ Person completing form _____ Today's date _____

Clinical issues	Currently a problem?	Evaluations needed	Treatment recommendations	Referrals made	Date for status check
<i>Dental Care</i>					
<i>Ambulation and Mobility</i> Describe current ambulatory status Questions about physical therapy, braces, adaptive equipment Need for power-drive wheelchair					
<i>Seating and Positioning</i>					
<i>Upper-Extremity Function and Visual Motor Skills</i>					
<i>Musculoskeletal Problems</i> Recent change in contractures, gait, scoliosis					
<i>Associated Developmental or Learning Issues</i> Current school achievement Review early intervention (EI) or school services (individualized family service plan [IFSP] or individualized education program [IEP]) Developmental delay or mental retardation Learning disabilities					

Family and Physician Management Plan Summary for Children and Adolescents with Cerebral Palsy (continued)

Child's name _____ Person completing form _____ Today's date _____

Clinical issues	Currently a problem?	Evaluations needed	Treatment recommendations	Referrals made	Date for status check
<i>Associated Behavior/Mental Health Problems</i>					
<i>Social Skills</i> Involvement in peer group activities in school and community (determine which supports are needed)					
<i>Self-Care/Independence</i>					
<i>Family Support Services</i>					
<i>Treatment of Hypertonicity</i>					
<i>Communication/Speech</i> Questions about speech services Need for augmentative and alternative communication (AAC) device(s) or a computer for written communication					

Family and Physician Management Plan Summary for Children and Adolescents with Cerebral Palsy (continued)

Child's name _____ Person completing form _____ Today's date _____

Clinical issues	Currently a problem?	Evaluations needed	Treatment recommendations	Referrals made	Date for status check
<i>Anticipatory Guidance</i> List issues discussed and materials provided					
<i>Collaboration with Community Agencies</i> School					
Comments					

Next update of the Management Plan Summary _____

Signature _____ Date _____
(Child and parent)

Signature _____ Date _____
(Health professional)

Musculoskeletal Examination Scoring Form

Child's name _____ Date of birth _____ Today's date _____

Diagnosis _____

Equipment/braces _____

Surgeries _____

Examiner _____

A. Structural changes

1. Joint contractures: Rate 0 (none), 1 (present), 2 (severe)^a

Hip	R _____	L _____	Elbow	R _____	L _____
Knee	R _____	L _____	Forearm	R _____	L _____
Ankle	R _____	L _____	Wrist	R _____	L _____
Toes	R _____	L _____	Thumb	R _____	L _____
Shoulder	R _____	L _____	Fingers	R _____	L _____

Please describe type of contracture (e.g., hip flexion contracture) _____

2. Straight-leg raising (popliteal angle): Rate 0 (full), 1 (limited), 2 (severely limited)

R _____ L _____

3. Hip subluxation or dislocation: Rate 0 (not present), 1 (suspect), 2 (definite)

R _____ L _____

4. Spine changes: Rate 0 (not present), 1 (present), 2 (severe)

Scoliosis _____ Lordosis _____ Kyphosis _____

5. Leg-length discrepancy in supine (in centimeters): R _____ L _____

Clinical difference in stance (in centimeters): _____

6. Foot and ankle deformities: Rate 0 (not present), 1 (present), 2 (severe)

R _____ L _____

Describe type _____

7. Rotational abnormalities of legs: Rate 0 (none), 1 (present), 2 (severe)

Femoral anteversion R _____ L _____

Internal or external tibial torsion R _____ L _____

8. Arm and/or hand deformities: Rate 0 (not present), 1 (present), 2 (severe)

R _____ L _____

Describe type _____

^a The normal range of motion for different joints is given in Section E at the end of this form. In general, a rating of *severe* or *severely limited* for any of the test items reflects a problem that has a marked impact on function. For example, a hip flexion contracture of greater than 30° usually makes independent standing and walking very difficult.

(continued)

Musculoskeletal Examination Scoring Form (continued)

9. Congenital defects Rate 0 (not present), 1 (present), 2 (severe)

R _____ L _____

Please describe _____

B. Muscle tone and strength

1. Trunk in sitting: Rate 0 (sits with trunk erect), 1 (trunk rounded, occasional use of hands for support), 2 (requires hands for support in sitting), or 9 (not able to sit) _____

Tone

Rate 0 (normal),
1 (definite hypertonicity),
2 (severe hypertonicity), or
9 (hypotonicity)

Strength

Rate 0 (normal),
1 (definite weakness),
2 (severe weakness), or
9 (cannot evaluate)

2. Upper extremity

Hand grip R _____ L _____

Shoulder extensors R _____ L _____

Biceps/brachioradialis R _____ L _____

Pronator teres R _____ L _____

3. Lower extremity

Hip adductors R _____ L _____

Rectus femoris R _____ L _____

Hamstrings R _____ L _____

Gastrocnemius/soleus R _____ L _____

Clonus present? R _____ L _____

Ankle dorsiflexion R _____ L _____

Coming to stand
(or coming to tall kneel) R _____ L _____

One-leg standing
(hip abductors) R _____ L _____

Walking on heels R _____ L _____

Walking on toes R _____ L _____

4. Other activities

Wheelbarrow walk
(or crawling) R _____ L _____

Push-up R _____ L _____

Sit-up R _____ L _____

C. Upper-extremity function

1. Involuntary movement, dysmetria, or dystonia _____

Please describe and note impact on function _____

2. Active range of motion: Rate 0 (full), 1 (limited), 2 (severely limited)

Elbow extension R _____ L _____

Supination R _____ L _____

Wrist extension R _____ L _____

Thumb abduction R _____ L _____

Thumb extension R _____ L _____

Finger extension R _____ L _____

(continued)

Musculoskeletal Examination Scoring Form (continued)

- Rate 0 (adequate), 1 (inadequate), 2 (severely impaired)
3. Grasp/release of block R _____ L _____
 Pincer grasp R _____ L _____

D. Observation of gait

1. Standing
 Rate 0 (not present), 1 (definite), 2 (severe) Rate 0 (adequate), 1 (inadequate), 2 (severely impaired)
- Pelvic obliquity, retraction, or anterior tilt R _____ L _____ Standing balance _____
- Hip adduction R _____ L _____
- Crouch (hip and knee flexion) R _____ L _____ Base of support (centimeters) _____
- In or out toeing R _____ L _____
- Equinus R _____ L _____
- Other foot and/or ankle deformities R _____ L _____

Comments _____

2. Walking without braces
 Rate 0 (not present), 1 (definite), 2 (severe) Rate 0 (adequate), 1 (inadequate), 2 (severely impaired)
- Exaggerated truncal sway with pelvic drop R _____ L _____ Clearance of foot R _____ L _____
- Pelvic obliquity, retraction, or anterior tilt R _____ L _____ Step length R _____ L _____
- Stability R _____ L _____ Velocity R _____ L _____
- Hip adduction R _____ L _____ Arm swing/posture R _____ L _____
- Crouch (hip and knee flexion) R _____ L _____
- In or out toeing R _____ L _____
- Equinus R _____ L _____
- Other foot and/or ankle deformities R _____ L _____

Comments _____

3. Walking with braces
 Rate 0 (not present), 1 (definite), 2 (severe) Rate 0 (adequate), 1 (inadequate), 2 (severely impaired)
- Exaggerated truncal sway with pelvic drop R _____ L _____ Clearance of foot R _____ L _____
- Pelvic obliquity or anterior tilt R _____ L _____ Step length R _____ L _____
- Hip adduction R _____ L _____ Stability R _____ L _____

(continued)

Musculoskeletal Examination Scoring Form (continued)

Crouch (hip and knee flexion) R _____ L _____ Velocity R ____ L ____
In or out toeing R _____ L _____ Arm swing/posture R ____ L ____
Equinus R _____ L _____
Other foot and/or ankle deformities R _____ L _____

Comments (Note the presence of ataxia, involuntary movement, or dystonia. List current braces and assistive devices, and note any differences when wearing braces.) _____

4. Ambulatory status (*please circle*)

Community ambulator

- Walks without braces or aids *or*
- Walks with braces or other aids, no wheelchair *or*
- Walks with braces or other aids, uses wheelchair for long distances

Household ambulator

- Walks with braces or other aids in home or school (classroom) only *and*
- Uses wheelchair for long distances

Nonfunctional ambulator

- Walks with braces or other aids only in therapy *and*
- Scoots or crawls and uses wheelchair for mobility

Nonambulator

- Rolls, scoots, or crawls and uses wheelchair for mobility
- Nonindependent mobility

E. Range of motion^b

Hip 130° flexion to 0°–10° extension
20°–30° adduction to 60° abduction (with hips flexed)^c
40°–50° internal to 30°–45° external rotation

Knee 120°–150° flexion to 5°–10° extension

Ankle 20°–30° dorsiflexion to 40°–50° plantarflexion

Shoulder 150°–170° forward flexion to 40° extension
95° internal to 40°–60° extension

Elbow 150° flexion to 0°–10° extension

Forearm 80°–90° pronation to 80°–90° supination

Wrist 50°–60° flexion to 35°–60° extension

^b Data from Hall, Froster-Iskenius, and Allanson (1989, pp. 281–285).

^c Data from Joint Motion Method of Measuring and Recording, American Academy of Orthopedic Surgeons (1965, pp. 84–85).