
Cerebral Palsy

CRITICAL ELEMENTS OF CARE

Produced by

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Seattle Children's Hospital, Seattle, WA**

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The *Critical Elements of Care* (CEC) considers care issues throughout the life span of the child. The intent of this document is to educate and support those caring for children with cerebral palsy. The CEC is intended to assist the primary care provider in the recognition of symptoms, diagnosis and care management related to a specific diagnosis. It provides a framework for a consistent approach to management of these children.

These guidelines were originally developed through a consensus process. The design team was multidisciplinary with state-wide representation involving primary and tertiary care providers, family members and a representative from a health plan. Subsequent revisions have utilized the best evidence based practice recommendations available at the time.

Content reviewed and updated 6/11 by John (Jeff) McLaughlin, MD, and William Walker, MD.

DISCLAIMER: *Individual variations in the condition of the patient, status of patient and family, and the response to treatment, as well as other circumstances, mean that the optimal treatment outcome for some patients may be obtained from practices other than those recommended in this document. This consensus-based document is not intended to replace sound clinical judgment or individualized consultation with the responsible provider regarding patient care needs.*

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INTRODUCTION TO CEREBRAL PALSY

Cerebral palsy is an excellent example of a medical condition that requires competent, comprehensive, continuous, compassionate and community-based care. It is critical that primary care providers (PCP) be involved and knowledgeable about the current and future care plan for the best outcome for each child. A team approach is required to develop this practice model. The team members may include community service providers such as public health departments, early intervention programs/schools or private therapy providers including occupational, physical and speech therapists. There is also a need for experienced teams of specialists based at regional centers who have experience in the treatment and management of individuals with cerebral palsy. The family is at the center of the care team.

What Is Cerebral Palsy?

Cerebral palsy is a group of disorders of movement and posture resulting from injury or malformation to the developing central nervous system. There are many causes for cerebral palsy, with onset ranging from preconception to an arbitrary point such as 24 months of age. The neurologic impairment is nonprogressive, although secondary disability can occur. Characteristics of cerebral palsy change with developmental stages, especially in the first few years of life. This impairment and resultant disability are both permanent.

How Common Is Cerebral Palsy?

Over the last 20 years the birth incidence of CP has been steady between 2 and 2.5 cases per 1,000 live births. Alarming, the most recent estimate of prevalence in children from the CDC is 3.6 per 1,000 in school age children. There is essentially no mortality due to CP except in children who cannot roll over or swallow on their own. This small group of children has a high mortality rate. Most children with CP have a long adult life span ahead so that care in childhood should take adult function and participation into account.

How Is Cerebral Palsy Diagnosed?

The diagnosis of cerebral palsy is essentially clinical and is highly dependent on the physician's knowledge of normal motor development and its variants. In all but the mildest cases, the diagnosis of cerebral palsy can be made by 12-18 months of age. A thorough search for etiologies is warranted in the young child newly diagnosed with cerebral palsy. This includes a thorough history and physical, plus follow-up observation of the progression of motor abilities at frequent intervals. Physicians experienced with this disorder, such as developmental pediatricians, neurologists and geneticists, can be consulted to aid in the diagnosis.

To aid in confirming the diagnosis and ruling out neoplastic or progressive causes for motor disability such as metabolic and neurodegenerative disorders, magnetic resonance imaging (MRI) is usually indicated. The imaging can usually wait until a child can undergo the study without sedation or done in conjunction with another procedure. Other diagnostic testing may include cultures, immune status, metabolic screening, karyotyping, genetic probes or confirmatory tests for other specific disorders. EEGs, EMGs and skull films are not useful for the diagnosis of cerebral palsy or its etiology.

How Are the Patterns of Cerebral Palsy Described?

Cerebral Palsy (CP) represents a group of disorders of variable etiology and variable clinical presentation. Efforts to characterize individuals with CP may occur for a variety of reasons: clinical description, prediction of future status, and to monitor changes in function. These methods incorporate information from several dimensions:

1. **Topography of the Impairment:** the parts of the body that are involved (quadriplegia, hemiplegia, diplegia)
2. **Type of Impairment:** is the body stiff (spastic – most common), loose (hypotonic) or exhibiting abnormal motor control (athetoid, ataxic, dystonic)

3. **Severity of Mobility Limitations:** the Gross Motor Function Classification System, which ranks severity on a five-point scale by age groups, is the best way to describe severity (see below)

Studies have demonstrated that injuries to certain areas of the brain result in consistent patterns of impairment. This observation has led to the “topographical” descriptors of various spastic forms of cerebral palsy such as hemiplegia, diplegia or quadriplegia, which are thought to be the result of pyramidal tract injury. Certain patient populations are predisposed to a particular “type” of cerebral palsy, as in the case of premature infants and spastic diplegia. The extrapyramidal types of cerebral palsy (athetoid, dystonic, ataxic) will typically involve the entire body. Many children have a “mixed” clinical picture, where both spastic (pyramidal) and extrapyramidal features are present.

What Are the Causes of Injury in Cerebral Palsy?

The injury resulting in cerebral palsy may occur during the prenatal (including genetic), perinatal or postnatal periods. The majority of cases are prenatal. Many children with cerebral palsy appear to have a “cascade” of harmful events that often begin in utero and continue during and after delivery. The precise etiology often cannot be identified in 20-30% of cases. True perinatal asphyxia at or near term causes a small percentage of cerebral palsy cases.

Are There Associated Risks of Other Disabilities?

Yes, cerebral palsy is known to have a higher risk association with other disabilities. These risks include, but are not limited to:

- Seizures: 35-45%
- Intellectual disability: 40-60%
- Visual impairments: 20-60%
- Communication impairments, including hearing: 30%
- Feeding difficulties
- Behavioral concerns
- Sleep problems

In children with cerebral palsy, multiple disabilities tend to be the rule rather than the exception; 80% will have at least one associated disability, while 40% will have three or more associated disabilities. Despite these multiple challenges, many children with CP can become healthy, productive adults.

How Is the Severity of Cerebral Palsy Described?

Traditional methods to classify the severity of CP have limited reliability and validity. Newer systems, including the Gross Motor Function Classification System (GMFCS) have been created and validated to consistently describe gross motor function among examiners. The Gross Motor Functional Classification System (GMFCS) defines five levels of motor function for each age group (see www.canchild.ca and look under Motor Growth Measures for GMFCS-ER). Both researchers and clinicians now use the GMFCS to compare groups of children with cerebral palsy and to describe individual children in medical records.

Children who have GMFCS I or II severity are ambulatory. Children who have GMFCS III severity can transfer independently and walk with assistive devices for short distances. Children who have GMFCS IV or V severity require devices such as power mobility and the assistance of other people. The overall severity of a given child’s impairment is often determined by the other disabilities that can accompany CP.

Does the Presenting Picture of Cerebral Palsy Stay the Same?

No, cerebral palsy exhibits an evolving clinical picture over time, secondary to the maturation of the central nervous system; therefore clinical change should be expected. Because of this “time effect,” predictions about prognosis are rarely absolute. The clinical evaluation of these children must be ongoing and outcomes should be carefully assessed and reassessed.

A changing clinical picture may be the natural progression of the primary injury, modified by maturation of the central nervous system (i.e., increasing tone or spasticity), or it may be a “new”

finding identified by assessment methods that are age-dependent (delayed language or cognitive abilities). The clinical change may also be a result of the emergence and/or identification of other associated deficits. The evolving appearance of signs and symptoms of cerebral palsy, such as changes from hypotonia to spasticity, need to be distinguished from progressive disorders such as those caused by metabolic, neoplastic or degenerative disorders.

How Can the Child with Cerebral Palsy Be Best Managed?

The strategic goals in the management of cerebral palsy are to enable the child to grow up in the family and community and to achieve optimal independent participation in adult life. Comfort and ease of care are additional valued goals.

Much of the tactical management of cerebral palsy is aimed at preventing cumulative secondary impairment and disability. Follow-up at regular intervals (directed at assessing motor and developmental progress) is essential in the optimal management of a child with cerebral palsy.

The multi-faceted nature of cerebral palsy requires a comprehensive approach. No two cases with cerebral palsy are alike. Interventions directed at one aspect of the child's problem must be made while taking into account the potential impact they may have on all areas. Prioritization is crucial. A team of experienced professionals is usually needed at both the primary and consultative level.

What Are Some Valuable Characteristics of Optimal Care?

Effective health care systems for children should be *family-centered, competent, comprehensive, compassionate, continuous, community-based* and *culturally appropriate*.

- **Family-centered care** encompasses an understanding of the child's place in the family and the impact of the disability on all family members. The family is empowered to play a major role in decision-making for their child. Through meetings, educational materials and copies of all professional reports, families are provided the background necessary for making informed decisions.

- An effective health care system is a **comprehensive** source for the patient's routine, as well as, specialty care needs. A child's cerebral palsy does not prevent her from contracting ordinary childhood diseases, such as ear infections and influenza, nor exclude her from anticipatory care needs, such as immunizations and monitoring of physical growth.
- **Continuity** for these children and their families is essential. Following these children over time permits monitoring of the progression of their disability and reduces redundancy of evaluations. Continuity fosters an anticipation of medical, educational and community needs for the child and the family and the prevention of further complications through early identification and treatment.
- **Competence** requires that professionals have current training, experience, judgment and interest in cerebral palsy. No single provider has the time or expertise to address all of the affected functional areas and effectively manage these children while supporting their families.
- A **community-based** approach requires appropriate use of community resources in areas of special education, family support systems, financial support, respite, child care, recreation and social participation.
- A **compassionate** approach emphasizes the child, not the disability. Long-term stressors are anticipated and countered with appropriate care and support. Rules are adjusted to serve individual wants and needs. Self-defined choices for quality of life are respected.

When Are Interventions and Treatments Indicated?

Treatment for children with cerebral palsy should be centered around improved activity, participation and independence for the child and the family - now and into the future. Interventions and therapies should not be mandated based on the "label" of cerebral palsy. The effectiveness of any intervention is optimized by periodic review and modification with a constant goal of improving function. Neither the clinical presentation nor the clinical treatment should be expected to remain static. Anticipating

clinical changes allows for improved monitoring and planning for necessary interventions.

Who Can Help in Monitoring the Need for Interventions or Treatments?

Community and regional resources can assist the PCP and family in making decisions about services. Early intervention centers, schools and a local therapist can monitor the progression of the child's abilities. Experienced cerebral palsy teams will provide the PCP with extended assessment abilities and intervention programs needed to assist the child and family.

What Are Some of the Specific Management Issues That Can Occur?

Spasticity and Dystonia

Symptoms such as spasticity and dystonia evolve over time and can become problematic. When this happens pharmacologic or surgical interventions are available. Community therapists can help monitor for these concerns. By developing a working relationship with these professionals, the PCP will be able to intercede appropriately. The PCP can use the cerebral palsy team to develop a plan of care for these problems.

Pain

Pain is a common problem in children with cerebral palsy at all ages. Many children are remarkably stoic so the provider needs to ask about pain. Pain is most often due to either musculoskeletal problems, spasm from spasticity or gastrointestinal issues such as reflux and constipation. It is important to search for and eliminate causes of pain and to treat pain vigorously. Muscle spasm due to fatigue or severe spasticity is common.

Sleep Problems

Sleep problems are common in children with cerebral palsy at all ages. The causes can be complex but can also be due to typical developmental issues. Parents may be more likely to respond to wakening in a child with a disability like cerebral palsy for many logical reasons but can also reinforce repeated wakening. Airway problems are common in young children with tonsillar hypertrophy and in older

adolescents with acquired jaw deformities. Central and obstructive apnea may be present. Children with severe visual impairment may not have a normal circadian clock.

Musculoskeletal Changes

Musculoskeletal changes are often the most easily identified consequences of central nervous system injury in cerebral palsy. Interventions may address the physical changes of contracture, muscle imbalance, joint instability and body malalignment with the goals of preventing deformity, improving function and relieving pain. Professionals participating in the care of these children should consider the impact any intervention will have on function. Everyone involved should encourage input from other professionals who are working with the children, therapists and parents. A thorough orthopedic assessment should include a detailed visual inspection (e.g. gait observation), a hands-on inspection of joint mobility (e.g. passive range of motion) and an assessment of joint alignment.

Contractures are more likely in children with spasticity than others. There have been specific musculoskeletal problem areas identified in this patient population. Spasticity in the hip adductors may result in subluxation of the femoral head. Dislocations of the hips are more common in nonambulatory children when compared to ambulatory children. Subluxation can reach an advanced stage before becoming clinically apparent. The hip needs to be relocated in the socket by age 4-5 years to develop properly. There is ample evidence from prospective studies to support obtaining hip X-rays beginning between 18-24 months as a standard of practice. The frequency of subsequent X-rays depends on hip status and severity of spasticity. Gonad shielding should be routine.

Scoliosis is the appreciable deviation of the normally straight vertical line of the spine. Children with cerebral palsy are at risk for scoliosis, especially during times of rapid growth, such as the pubertal growth spurt. A simple lateral deviation of the spine is not a cause for concern. The presence of a twist or rotation around the vertical axis warrants x-rays and orthopedic consultation. In ambulatory children, the incidence of scoliosis is less than 10% and usually

appears during the pubertal growth spurt. There is a 30-40% incidence of scoliosis in non-ambulators. Their scoliosis is more likely to be lumbar and is often associated with pelvic obliquity.

Management decisions in the treatment of scoliosis should consider the degree of curvature, the proximity to the age of skeletal maturity and the linear growth rate of the child. While there is no compelling evidence that physical therapy, custom seating, or any treatment for hypertonia can prevent the progression of scoliosis, all of these treatments have important roles in helping a child achieve and maintain function.

The goals of orthopedic intervention for scoliosis should be: to maintain balance in both the sitting and walking positions; to reduce pain; to reduce areas of increased pressure resulting in decubitus; and to preserve cardiopulmonary functional reserve. It is important that surgical repair of scoliosis be undertaken by an orthopedist who has experience with individuals with cerebral palsy and in a center with strong postoperative and rehabilitation care teams.

Therapy and Bracing

Therapy and bracing concerns can be evaluated in the community by therapists, rehabilitation medicine physicians and orthopedists. Therapy is more effective when directed toward functional goals (such as getting up stairs, versus increased ankle dorsiflexion). The importance of strengthening, practice and maintenance of cardiopulmonary endurance deserves considerable emphasis beginning in the preschool years and continuing through adulthood for individuals with cerebral palsy. There is ample evidence that muscle strengthening is beneficial and does not worsen hypertonia. Referral to experienced cerebral palsy teams at regional centers is often helpful.

Adaptive Equipment

Adaptive equipment needs begin at an early age when the child's need for safety is addressed. The family may need equipment to bathe, transport or position their child in a safe manner. Community therapists, in association with early intervention centers/schools, can assist the PCP in determining

how best to address these needs. If the child's needs are difficult to meet, it may be necessary to refer to an experienced cerebral palsy team for evaluations and recommendations.

Seizures

Seizures also require careful evaluation and follow-up in children with cerebral palsy. Overall, 35-45% of these children will have some kind of seizure disorder. The onset of seizures can occur at any time, but usually begins during the first two years of life. Seizures can be of any clinical type, though grand mal seizures are reported most frequently. There is a strong correlation between the clinical type of cerebral palsy and the incidence of seizures. There is a higher incidence of seizures in children with hemiplegic and quadraplegic (60%) cerebral palsy. Seizures are relatively uncommon in spastic diplegia (15-30%), and in the extrapyramidal forms (<25%).

Cognitive Abilities

Cognitive abilities should be specifically assessed and must be considered as a comprehensive treatment plan is developed. Overall, 40-60% of children with cerebral palsy will have an intelligence quotient below 70 within the range defined for intellectual disability. The severity and frequency of intellectual disability is related to the clinical type of cerebral palsy. More than 75% of children with hemiplegia, diplegia and athetoid cerebral palsy have normal intelligence, while 75% of children with spastic quadriplegia have intellectual disability. Children with cerebral palsy who have a normal intelligence quotient are often at risk for learning disabilities.

It is known that a high percentage of the children with severe motor disabilities also have communication difficulties. There is a close linkage between communication skills and the outcome of cognitive testing. Therefore it is imperative that the impact of these deficits on the testing procedures and the child's communication and language skills optimized prior to the initiation of cognitive assessments.

Visual Impairment

Visual impairment is present in more than half of children with CP. Refractive errors (often severe)

and strabismus (esotropias > exotropias) are most common, but nystagmus, cortical visual impairment, visual field defects and complex disorders of visual control may all be encountered.

Hearing Problems

Hearing problems are estimated to be present in 10-15% of children with cerebral palsy. An accurate measure of hearing ability is essential. While universal newborn hearing screening is essential, children with CP may develop permanent hearing loss after the newborn period.

Oral Motor Deficits

Oral motor deficits (dysarthria) can adversely affect the individual's speech and feeding abilities. The child may have a central speech/language deficit such as aphasia or a central deficit in motor planning (apraxia).

Feeding/Nutrition

Careful monitoring of the weight and length/height are critical in determining the proper growth of the child. Good nutritional status is essential for healing following surgery. The risk for feeding and nutritional concerns in children with cerebral palsy, including osteopenia, increases with the degree and severity of the disability. Risk factors for vitamin D deficiency include lack of ambulation, anticonvulsant use, low sun exposure and living above 40 degrees latitude, poor calcium intake and general malnutrition. Providers should assure that all children with CP receive at least 400 international units per day of vitamin D to maximize bone density and should check 25-hydroxy vitamin D levels yearly.

Special techniques are required to measure bone density accurately by DEXA scan. DEXA scans and bisphosphonate treatment are best reserved for children with CP who have a personal history of low-impact fractures. At present, there are no data on the safety of bisphosphonates given in childhood and continued for a lifetime. Those with poor calcium intakes should be supplemented with calcium (500 to 1,300 mg/day, depending on weight).

Gastrointestinal Problems

Gastrointestinal problems (gastroesophageal reflux, GI motility disorders and constipation) are common

in nonambulatory children with CP. Constipation is common and should be treated vigorously with adequate fluids, stool softeners, bowel stimulants, comfortable adaptive toilet seats and other techniques. While gastrostomy/jejunostomy technology and special formulas make it easier to assure the nutritional well-being of children with severe CP, management issues including the need for other surgical interventions (fundoplication, etc.) may further complicate the decision-making process.

Emotional Support

Emotional support for the family is important. All family members are affected when one member has a disability. Family stress is intensified by the care needs of the child. The PCP can help the family find support through Washington State Parent to Parent or PAVE - Parents Are Vital in Education (see references). The local public health department, early intervention centers/schools and other agencies may help identify other resources to assist the family. If these services are not locally available, then referrals to an experienced cerebral palsy team may be of assistance.

Critical Elements of Care

The following outline defines functional areas that need to be assessed and the recommended frequency for assessment. It also provides the PCP with suggestions for appropriate consultations with other specialists, including developmental pediatricians, orthopedists, neurologists, physiatrists (rehabilitation specialists), speech therapists, physical and occupational therapists, nutritionists, psychologists, social workers, educators, public health nurses, equipment vendors and others. Along with these specialists, life-long care always involves the child's family and requires their thoughtful involvement in all decision making. These Critical Elements of Care constitute an initial attempt to provide a framework for long-term management of such children and should not be viewed as a comprehensive manual for care.

GUIDELINES FOR CRITICAL ELEMENTS OF CARE

How To

The *Critical Elements of Care for Cerebral Palsy* were designed to organize and simplify the child's care plan. They provide information and education regarding the comprehensive needs of an individual with cerebral palsy.

The Critical Elements of Care are divided into five age groupings:

- < 2 years
- 2-4 years
- 4-6 years
- 6-12 years
- >12 years

Within each age grouping, six functional categories are identified:

- Communication
- Feeding and Nutrition
- Musculoskeletal
- Mobility
- Cognition
- Sensory Impairment

In addition, there is a section for Family Issues.

Each age grouping has been divided into functional categories. These are subdivided into a range of functional levels and coincide with specific recommendations for intervention possibilities.

By reviewing the Critical Elements of Care specific to your patient's age group, you will be able to assess the areas of concern, identify the intervention possibilities and organize and simplify the child's care plan.

WORKSHEET

The Quick Check Worksheet was designed to summarize the Critical Elements of Care using a check-off format to identify concerning trends over time. There is room for short notation regarding specific problems, treatment regimes or referral options. The worksheet may be used during each office visit to consolidate the information. Therefore, past and present concerns can be identified quickly, and intervention referrals initiated.

Critical Elements of Care: Cerebral Palsy

AGE < 2 YEARS		
AREAS OF CONCERN	ASSESSMENT & INTERVENTION	SERVICE COORDINATION
Communication		
VERBAL	<ul style="list-style-type: none"> Assessment of communication (expressive and receptive) for age/developmental levels 	
NONVERBAL	<ul style="list-style-type: none"> Repeat audiologic assessment regardless of newborn hearing screen result Review assessment/plan of the early intervention program Consider simple augmentative communication devices (picture boards, adaptive switches, etc.) 	<ul style="list-style-type: none"> ENT/audiologist Early intervention program*
Musculoskeletal		
CONTRACTURE ABSENT	<ul style="list-style-type: none"> Assess ROM every 6 mo. extremities, hips and back Hip X-ray at 18-24 months Ask about pain 	
CONTRACTURE PRESENT	<ul style="list-style-type: none"> Assess ROM every 6 month: extremities, back Orthopedic evaluation every 6 months, if indicated Hip X-ray at 18-24 months Ask about pain Review OT/PT plan (splinting/bracing) 	<ul style="list-style-type: none"> Orthopedic consult Early intervention program*
Cognition		
AGE-APPROPRIATE	<ul style="list-style-type: none"> Assess per well-child practice guidelines 	
DELAYED	<ul style="list-style-type: none"> Need formal evaluation to accurately determine degree of cognitive delay (once in this age period) Consider associated disabilities when choosing appropriate instrument for testing 	<ul style="list-style-type: none"> Early intervention program* Experienced cerebral palsy management team
Feeding & Nutrition		
ORAL	<ul style="list-style-type: none"> Assess per well-child practice guidelines Plot weight, length, OFC Maintain weight-length ratio at 5-50th percentile Review drug-nutrient interaction Assess feeding, swallowing skills (duration, parent concerns) Consider nutrition consult Consider behavioral component / Oral aversions OT consult (early intervention program, experienced cerebral palsy management team) May need calorie or nutrient modifications (special supplements) Supplement with 400 IU vitamin D Measure 25-hydroxy vitamin D levels annually Consider supplementation with calcium (500 mg/day) 	<ul style="list-style-type: none"> WIC (ages 1-5) Health Dept. Early intervention program*
NON-ORAL	<p>Assess at each visit:</p> <ul style="list-style-type: none"> Plot weight, length, OFC Maintain weight-length ratio at 5-50th percentile Review drug-nutrient interactions Evaluate feeding, swallowing difficulties Review history of pulmonary problem, recurrent OM and sinusitis Ask about pain Consider delayed gastric emptying and gastroesophageal reflux Consider nutrition consult, OT feeding evaluation, or swallow evaluation (experienced cerebral palsy management team) Consider behavioral component Pediatric surgical consultation, as indicated Assess nasogastric/gastrostomy/jejunostomy tube site if indicated Supplement with 400 IU vitamin D Measure 25-hydroxy vitamin D levels annually Consider supplementation with calcium (500 mg/day) 	<ul style="list-style-type: none"> WIC (ages 1-5) Health Dept. Early intervention program* Experienced cerebral palsy management team

Critical Elements of Care: Cerebral Palsy

AGE < 2 YEARS		
AREAS OF CONCERN	ASSESSMENT & INTERVENTION	SERVICE COORDINATION
Mobility		
ASSISTED INDEPENDENT or AMBULATOR (GMFCS I, II, III)**	<ul style="list-style-type: none"> • Visits per well-child practice guidelines • Yearly assessment of gross motor function and plan for recommendations • Consider PT/OT, adaptive equipment needs • Consult with an experienced cerebral palsy management team 	<ul style="list-style-type: none"> • Early intervention program* • Experienced cerebral palsy management team
NON-AMBULATOR (GMFCS IV, V)	<ul style="list-style-type: none"> • Yearly assessment of gross motor function and plan • Consider PT/OT, adaptive equipment • Consult with an experienced cerebral palsy management team 	<ul style="list-style-type: none"> • Early intervention program* • Experienced cerebral palsy management team
Sensory Impairment		
HEARING NORMAL	<ul style="list-style-type: none"> • Assess per well-child practice guidelines 	
HEARING ABNORMAL	<ul style="list-style-type: none"> • Refer to ENT/audiology • Consider referral to early intervention program for speech therapy, amplification, sign language 	<ul style="list-style-type: none"> • Early intervention program* • Experienced cerebral palsy management team
VISION NORMAL	<ul style="list-style-type: none"> • Assess per well-child practice guidelines check acuity and binocularity 	
VISION ABNORMAL	<ul style="list-style-type: none"> • Referral to ophthalmology 	<ul style="list-style-type: none"> • Early intervention program*, visually impaired programs
Family Issues		
<ul style="list-style-type: none"> • Anticipate family's needs • Sleep issues for the child and caregivers • Acceptance/understanding of diagnosis (across all functional areas) • How to explain to siblings/family members • Resources: support groups, respite care, information, financial (SSI, CSHCN, DDD), or contact PHN for further resources • Literature resources, how to care for a child with CP (see references and resources section) • Establish mutual goals between family and provider • Address emotional issues: grief, loss (ongoing) • Foster care, institutional care options and/or respite care • Lifestyle changes for family, transportation (car seats) and safety issues, • Specific issues for child and family: <p>* Annual renewal of prescriptions for needed therapies. ** Robert Palisano, Peter Rosenbaum, Doreen Bartlett, Michael Livingston, 2007 CanChild Centre for Childhood Disability Research, McMaster University http://motorgrowth.canchild.ca/en/GMFCS/resources/GMFCS-ER.pdf</p>		

Critical Elements of Care: Cerebral Palsy

AGE 2-4 YEARS		
AREAS OF CONCERN	ASSESSMENT & INTERVENTION	SERVICE COORDINATION
Communication		
VERBAL	<ul style="list-style-type: none"> Assess expressive/receptive skills for age/developmental levels 	
NONVERBAL	<ul style="list-style-type: none"> Check hearing if not previously done Consider assessment/review plan with the early intervention/school for augmentative communication program Assistive technology specialist (experienced cerebral palsy management team) may be needed Enroll in developmental preschool at 3 years old 	<ul style="list-style-type: none"> ENT/audiologist Early intervention program*
Musculoskeletal		
CONTRACTURE ABSENT	<ul style="list-style-type: none"> Assess ROM (extremities, back) every 6-12 months Ask about pain 	
CONTRACTURE PRESENT	<ul style="list-style-type: none"> Assess ROM every 6 mo. (extremities, back) Ask about pain Hip/spine X-ray, as indicated Review OT/PT plan CP specialist every 6-12 months 	<ul style="list-style-type: none"> CP specialist Early intervention program*
Cognition		
AGE APPROPRIATE	<ul style="list-style-type: none"> Assess per well-child practice guidelines 	
IMPAIRED	<ul style="list-style-type: none"> Need formal evaluation to accurately determine degree of cognitive delay (once in this age period) Consider associated disabilities when choosing appropriate instrument for testing Enroll in developmental preschool at 3 years old 	<ul style="list-style-type: none"> Early intervention program* Experienced cerebral palsy management team
Feeding & Nutrition		
ORAL	<ul style="list-style-type: none"> Assess per well-child practice guidelines Plot weight, length, OFC Maintain weight-length ratio at 5-50th percentile Review drug-nutrient interaction Assess feeding, swallowing skills (duration, parent concerns) Consider: nutrition consult (WIC, Health Dept., experienced cerebral palsy management team) Consider behavior component/oral aversions OT consult (early intervention program, experienced cerebral palsy management team) May need calorie or nutrient modifications Supplement with 400 IU vitamin D Measure 25-hydroxy vitamin D levels annually Consider supplementation with calcium (500 mg/day) 	<ul style="list-style-type: none"> WIC (ages 1-5) Health Dept. Early intervention program*
NON-ORAL	<p>Assess at each visit:</p> <ul style="list-style-type: none"> Plot weight, length, OFC Maintain weight-length ratio at 5-50th percentile Review drug-nutrient interactions Evaluate feeding, swallowing difficulties Review history of pulmonary problem, recurrent OM and sinusitis Ask about pain Consider delayed gastric emptying and gastroesophageal reflux Consider nutrition consult, clinical feeding evaluation, and/or swallow evaluation Consider behavioral component Pediatric surgical consultation, as indicated Assess gastrostomy/jejunostomy tube care site Supplement with 400 IU vitamin D Measure 25-hydroxy vitamin D levels annually Consider supplementation with calcium (500 mg/day) 	<ul style="list-style-type: none"> WIC (ages 1-5) Health Dept. Early intervention program* Experienced cerebral palsy management team

Critical Elements of Care: Cerebral Palsy

AGE 2-4 YEARS		
AREAS OF CONCERN	ASSESSMENT & INTERVENTION	SERVICE COORDINATION
Mobility		
ASSISTED INDEPENDENT or AMBULATOR (GMFCS I, II, III)**	<ul style="list-style-type: none"> Yearly assessment to monitor gross motor function, assess for changing needs and to update recommendations Consider PT/OT, adaptive equipment needs Consult with an experienced cerebral palsy management team Assess potential for power mobility Encourage adaptive sports and aerobic exercise, especially swimming 	<ul style="list-style-type: none"> Early intervention program* Experienced cerebral palsy management team Coordinate with school/experienced cerebral palsy management team
NON-AMBULATOR (GMFCS IV, V)	<ul style="list-style-type: none"> Yearly assessment of gross motor function and plan Consider PT/OT, adaptive equipment needs Consult with an experienced cerebral palsy management team Encourage adaptive bicycling or swimming as an opportunity for aerobic conditioning 	<ul style="list-style-type: none"> Early intervention program Experienced cerebral palsy management team
Sensory Impairment		
HEARING NORMAL	<ul style="list-style-type: none"> Repeat audiologic assessment regardless of newborn screening results 	
HEARING ABNORMAL	<ul style="list-style-type: none"> Refer to ENT/audiology (local/experienced cerebral palsy management team) Coordinate assessment/plan with programs Consider speech therapy, amplification, sign language Refer to experienced cerebral palsy management team as indicated 	<ul style="list-style-type: none"> Early intervention program* School program* Parent education Experienced cerebral palsy management team
VISION NORMAL	<ul style="list-style-type: none"> Assess per well-child practice guidelines check acuity and binocularity 	
VISION ABNORMAL	<ul style="list-style-type: none"> Referral to ophthalmology (local/experienced cerebral palsy management team) 	<ul style="list-style-type: none"> Early intervention program* School program* Parent education Experienced cerebral palsy management team
Family Issues		
<ul style="list-style-type: none"> Ascertain family acceptance Sleep issues for the child and caregivers Parent separation issues - independence of child Changes in family lifestyle Getting ready for school issues Encourage age-appropriate activities Beginning peer relations Include child in family responsibilities, e.g. household chores Specific issues for child and family: <p>* Annual renewal of prescriptions for needed therapies ** Robert Palisano, Peter Rosenbaum, Doreen Bartlett, Michael Livingston, 2007 CanChild Centre for Childhood Disability Research, McMaster University http://motorgrowth.canchild.ca/en/GMFCS/resources/GMFCS-ER.pdf</p>		

Critical Elements of Care: Cerebral Palsy

AGE 4-6 YEARS		
AREAS OF CONCERN	ASSESSMENT & INTERVENTION	SERVICE COORDINATION
Communication		
VERBAL	<ul style="list-style-type: none"> Assess expressive/receptive skills for age/developmental levels 	
NONVERBAL	<ul style="list-style-type: none"> Check hearing if not previously done Assess/review school program Consider assessment/review plan with the school for augmentative communication program. Assistive technology specialist may be needed 	<ul style="list-style-type: none"> ENT/audiologist School program*
Musculoskeletal		
CONTRACTURE ABSENT	<ul style="list-style-type: none"> Assess ROM yearly (extremities, back) Ask about pain 	
CONTRACTURE PRESENT	<ul style="list-style-type: none"> Assess ROM yearly (extremities, back) Hip/spine X-ray, as indicated Ask about pain CP team evaluation yearly 	<ul style="list-style-type: none"> School program* CP specialist consult (local/experienced cerebral palsy management team)
Cognition		
AGE APPROPRIATE	<ul style="list-style-type: none"> Assess skills for age/developmental level 	
IMPAIRED	<ul style="list-style-type: none"> Review school program Need formal evaluation to accurately determine degree of cognitive impairment (once in this age period) Verbal and fine motor impairments may falsely lower scores on many standard IQ tests 	<ul style="list-style-type: none"> School program* Experienced cerebral palsy management team
Feeding & Nutrition		
ORAL	<ul style="list-style-type: none"> Assess per well-child practice guidelines Plot weight, length, OFC Maintain weight-length ratio at 5-50th percentile Review drug-nutrient interaction Assess feeding, swallowing skills (duration, parent concerns) Consider nutrition consult Behavioral component Consider feeding consult May need calorie or nutrient modifications Supplement with 400 IU vitamin D Measure 25-hydroxy vitamin D levels annually Consider supplementation with calcium (500 mg/day) 	<ul style="list-style-type: none"> Health Dept. Experienced cerebral palsy management team School program
NON-ORAL	<p>Assess at each visit:</p> <ul style="list-style-type: none"> Plot weight, length, OFC Maintain weight-length ratio at 5-50th percentile Review drug-nutrient interactions Evaluate feeding, swallowing difficulties Review history of pulmonary problem, recurrent OM and sinusitis Ask about pain Consider delayed gastric emptying and gastroesophageal reflux Consider nutrition consult, OT feeding evaluation, or swallow evaluation Consider behavioral component/oral aversions Pediatric surgical consultation, as indicated Assess gastrostomy/jejunostomy tube care site Supplement with 400 IU vitamin D Measure 25-hydroxy vitamin D levels annually Consider supplementation with calcium (500 mg/day) 	<ul style="list-style-type: none"> Health Dept. Experienced cerebral palsy management team

Critical Elements of Care: Cerebral Palsy

AGE 4-6 YEARS		
AREAS OF CONCERN	ASSESSMENT & INTERVENTION	SERVICE COORDINATION
Mobility		
INDEPENDENT AMBULATOR (GMFCS I, II)**	<ul style="list-style-type: none"> Yearly assessment to monitor for possible changing needs Encourage adaptive sports and aerobic exercise 	
ASSISTED AMBULATOR (GMFCS III)**	<ul style="list-style-type: none"> Yearly assessment of gross motor function and plan for recommendations Consider PT/OT, adaptive equipment Consult with an experienced cerebral palsy team Encourage adaptive sports and aerobic exercise, especially swimming 	<ul style="list-style-type: none"> School program* Experienced cerebral palsy management team
NON-AMBULATOR (GMFCS IV, V)	<ul style="list-style-type: none"> Yearly assessment of gross motor function and plan Consider PT/OT, adaptive equipment Consult with an experienced cerebral palsy team Assess potential for power mobility - coordinate with school/cerebral palsy management team Encourage adaptive bicycling or swimming as an opportunity for aerobic conditioning 	<ul style="list-style-type: none"> School program* Experienced cerebral palsy management team
Sensory Impairment		
HEARING NORMAL	<ul style="list-style-type: none"> Assess per well-child practice guidelines 	
HEARING ABNORMAL	<ul style="list-style-type: none"> New onset/changes: refer to ENT/audiology (local/experienced cerebral palsy management team) Coordinate assessment/plan with school program Consider speech therapy, amplification, augmentative communication evaluation 	<ul style="list-style-type: none"> ENT/audiologist School program* Experienced cerebral palsy management team
VISION NORMAL	<ul style="list-style-type: none"> Assess per well-child practice guidelines 	
VISION ABNORMAL	<ul style="list-style-type: none"> New onset/changes: refer to ophthalmology (local/experienced cerebral palsy management team) Coordinate assessment/plan with school program 	<ul style="list-style-type: none"> School program* Experienced cerebral palsy management team
Family Issues		
<ul style="list-style-type: none"> Address child's concerns: "Why am I different?" Sleep issues for the child and caregivers Encourage age-appropriate activities: summer camp, Special Olympics, horseback riding Encourage family participation in support groups: parents, child, siblings Include child in family responsibilities, e.g. household chores Specific behavioral concerns Specific issues for child and family: 		
<p>* Annual renewal of prescriptions for needed therapies. **Robert Palisano, Peter Rosenbaum, Doreen Bartlett, Michael Livingston, 2007 CanChild Centre for Childhood Disability Research, McMaster University http://motorgrowth.canchild.ca/en/GMFCS/resources/GMFCS-ER.pdf</p>		

Critical Elements of Care: Cerebral Palsy

AGE 6-12 YEARS		
AREAS OF CONCERN	ASSESSMENT & INTERVENTION	SERVICE COORDINATION
Communication		
VERBAL	<ul style="list-style-type: none"> Assess expressive/receptive skills for age/developmental levels 	
NONVERBAL	<ul style="list-style-type: none"> Check hearing if not previously done Assess/review school program Consider assessment/review plan with the school for augmentative communication program; assistive technology specialist 	<ul style="list-style-type: none"> ENT/audiologist School program* Experienced cerebral palsy management team
Musculoskeletal		
CONTRACTURE ABSENT	<ul style="list-style-type: none"> Assess ROM yearly (extremities, back) Ask about pain 	
CONTRACTURE PRESENT	<ul style="list-style-type: none"> Assess ROM yearly (extremities, back) Hip/spine X-ray, as indicated Ask about pain Orthopedic evaluation yearly, as indicated 	<ul style="list-style-type: none"> Orthopedic consult (local/experienced cerebral palsy management team) School program*
Cognition		
AGE APPROPRIATE	<ul style="list-style-type: none"> Assess skills for age/developmental level 	
IMPAIRED	<ul style="list-style-type: none"> Review school program Need formal evaluation to accurately determine degree of cognitive impairment (once in this age period) Verbal and fine motor impairments may falsely lower scores on many standard IQ tests 	<ul style="list-style-type: none"> School program* Experienced cerebral palsy management team
Feeding & Nutrition		
ORAL	<ul style="list-style-type: none"> Assess per well-child practice guidelines Plot weight, length, OFC Maintain weight-length ratio at 5-50th percentile Review drug-nutrient interaction Assess feeding, swallowing skills (duration, parent concerns) Consider nutrition consult (Health Dept., experienced cerebral palsy management team) Behavioral component OT consult (school, experienced cerebral palsy management team) May need calorie or nutrient modifications Supplement with 400 IU vitamin D Measure 25-hydroxy vitamin D levels annually Consider supplementation with calcium (500 mg/day) 	<ul style="list-style-type: none"> Health Dept. Experienced cerebral palsy management team
NON-ORAL	<p>Assess at each visit:</p> <ul style="list-style-type: none"> Plot weight, length, OFC Maintain weight-length ratio at 5-50th percentile Review drug-nutrient interactions Evaluate feeding, swallowing difficulties Review history of pulmonary problem, recurrent OM and sinusitis Ask about pain Consider delayed gastric emptying and gastroesophageal reflux Consider nutrition consult, OT feeding evaluation, or swallow evaluation (experienced cerebral palsy management team) Consider behavioral component/oral aversion Pediatric surgical consultation, as indicated Assess gastrostomy/jejunostomy tube care site Supplement with 400 IU vitamin D Measure 25-hydroxy vitamin D levels annually Consider supplementation with calcium (500 mg/day) 	<ul style="list-style-type: none"> Health Dept. Experienced cerebral palsy management team

Critical Elements of Care: Cerebral Palsy

AGE 6-12 YEARS		
AREAS OF CONCERN	ASSESSMENT & INTERVENTION	SERVICE COORDINATION
Mobility		
INDEPENDENT AMBULATOR (GMFCS I, II)**	<ul style="list-style-type: none"> Yearly assessment to monitor for possible changing needs Encourage adaptive sports and aerobic exercise 	
ASSISTED AMBULATOR (GMFCS III)**	<ul style="list-style-type: none"> Yearly assessment of gross motor function and plan for recommendations Components of plan: PT/OT, adaptive equipment Consult with an experienced cerebral palsy management team Encourage adaptive sports and aerobic exercise, especially swimming 	<ul style="list-style-type: none"> School program* Experienced cerebral palsy management team
NON-AMBULATOR (GMFCS IV, V)	<ul style="list-style-type: none"> Yearly assessment of gross motor function and plan Consider PT/OT, adaptive equipment Assess potential for power mobility – coordinate with school Consult with an experienced cerebral palsy management team Encourage adaptive bicycling or swimming as an opportunity for aerobic conditioning 	<ul style="list-style-type: none"> School program* Experienced cerebral palsy management team
Sensory Impairment		
HEARING NORMAL	<ul style="list-style-type: none"> Assess per well-child practice guidelines 	
HEARING ABNORMAL	<ul style="list-style-type: none"> New onset/changes: refer to ENT/Audiology (local/experienced cerebral palsy management team) Assess compliance with hearing aids as indicated 	<ul style="list-style-type: none"> School program* ENT/audiologist (local/experienced cerebral palsy management team)
VISION NORMAL	<ul style="list-style-type: none"> Assess acuity and binocularity Refer to ophthalmology as indicated 	<ul style="list-style-type: none"> Ophthalmology consult (local/experienced cerebral palsy management team)
VISION ABNORMAL	<ul style="list-style-type: none"> Assess compliance with use of glasses as indicated Refer to ophthalmology as indicated (local/experienced cerebral palsy management team) 	<ul style="list-style-type: none"> Ophthalmology consult (local/experienced cerebral palsy management team)
Family Issues		
<ul style="list-style-type: none"> Evaluate: Family transportation needs (van/lift) Sleep issues for the child and caregivers Ability to care for child (carrying, bathing, lifting, toileting, etc.) Puberty issues (behavioral, social) Peer relations Social activities (specialty camp, Special Olympics, etc.) Beginning discussing sexual issues: birth control, menstruation, self-exploration (possible GYN consult local/experienced cerebral palsy management team) Review: Care providers/sitters should be age/sex appropriate Start explicit discussions of planning for transition from pediatric to adult health care, school to work and taking on as much responsibility for self-management as possible Specific issues for the child and family: 		
<p>* Annual renewal of prescription for needed therapies. **Robert Palisano, Peter Rosenbaum, Doreen Bartlett, Michael Livingston, 2007 CanChild Centre for Childhood Disability Research, McMaster University http://motorgrowth.canchild.ca/en/GMFCS/resources/GMFCS-ER.pdf</p>		

Critical Elements of Care: Cerebral Palsy

AGE > 12 YEARS		
AREAS OF CONCERN	ASSESSMENT & INTERVENTION	SERVICE COORDINATION
Communication		
VERBAL	<ul style="list-style-type: none"> • Assess expressive/receptive skills for age/developmental levels 	
NONVERBAL	<ul style="list-style-type: none"> • Check hearing if not previously done • Assess/review school program • Consider assessment/review plan with the school for augmentative communication program 	<ul style="list-style-type: none"> • School program* • ENT/audiologist (local/experienced cerebral palsy management team)
Musculoskeletal		
CONTRACTURE ABSENT	<ul style="list-style-type: none"> • Assess ROM yearly (extremities, back) • Ask about pain 	
CONTRACTURE PRESENT	<ul style="list-style-type: none"> • Assess ROM yearly (extremities, back) • Hip/spine X-ray, as indicated • Ask about pain • Orthopedic evaluation yearly, as indicated 	<ul style="list-style-type: none"> • School program* • Orthopedic consult (local/experienced cerebral palsy management team)
Cognition		
AGE APPROPRIATE	<ul style="list-style-type: none"> • Assess skills for age/developmental level 	
IMPAIRED	<ul style="list-style-type: none"> • Review school program • Learning disabilities and “mild” fine motor problems may impair achievement without classroom adaptations. • Verbal and fine motor impairments may falsely lower scores on many standard IQ tests 	<ul style="list-style-type: none"> • School program* • Experienced cerebral palsy management team
Feeding & Nutrition		
ORAL	<ul style="list-style-type: none"> • Assess per well-child practice guidelines • Plot weight, length, OFC • Maintain weight-length ratio at 5-50th percentile • Review drug-nutrient interaction • Assess feeding, swallowing skills (duration, parent concerns) • Consider nutrition consult • Behavior component • Consider clinical feeding consult • May need calorie or nutrient modifications • Supplement with 400 IU vitamin D • Measure 25-hydroxy vitamin D levels annually • Supplement with calcium (500 mg/day) 	<ul style="list-style-type: none"> • Health Dept. • Experienced cerebral palsy management team
NON-ORAL	<p>Assess at each visit:</p> <ul style="list-style-type: none"> • Plot weight, length, OFC • Maintain weight-length ratio at 5-50th percentile • Review drug-nutrient interactions • Evaluate feeding, swallowing difficulties • Review history of pulmonary problem, recurrent OM and sinusitis • Ask about pain • Consider delayed gastric emptying and gastroesophageal reflux • Consider nutrition consult, clinical feeding evaluation, or swallow evaluation • Consider behavioral component / oral aversion • Pediatric surgical consultation, as indicated • Assess gastrostomy/jejunostomy tube care site • Supplement with 400 IU vitamin D • Measure 25-hydroxy Vitamin D levels annually • Supplement with calcium (500 mg/day) 	<ul style="list-style-type: none"> • Health Dept. • Experienced cerebral palsy management team

Critical Elements of Care: Cerebral Palsy

AGE > 12 YEARS		
AREAS OF CONCERN	ASSESSMENT & INTERVENTION	SERVICE COORDINATION
Mobility		
INDEPENDENT AMBULATOR (GMFCS I, II)**	<ul style="list-style-type: none"> Assess/refer for evaluation of driving skills, as indicated Encourage adaptive sports and aerobic exercise 	<ul style="list-style-type: none"> School program* Rehabilitation center
ASSISTED AMBULATOR (GMFCS III)**	<ul style="list-style-type: none"> Assess/refer for evaluation of driving skills/adaptive equipment, as indicated Yearly assessment of gross motor function and plan for recommendations Components of plan: PT/OT, adaptive equipment Consult with an experienced cerebral palsy management team Encourage adaptive sports and aerobic exercise, especially swimming 	<ul style="list-style-type: none"> School program* Experienced cerebral palsy management team
NON-AMBULATOR (GMFCS IV, V)	<ul style="list-style-type: none"> Assess/refer for evaluation of driving skills/adaptive equipment as indicated Yearly assessment of gross motor function and plan Consider PT/OT, adaptive equipment Consult with an experienced cerebral palsy management team Encourage adaptive bicycling or swimming as an opportunity for aerobic conditioning 	<ul style="list-style-type: none"> School program* Experienced cerebral palsy management team
Sensory Impairment		
HEARING NORMAL	<ul style="list-style-type: none"> Assess per well-child practice guidelines 	
HEARING ABNORMAL	<ul style="list-style-type: none"> New onset/changes: refer to ENT/audiology (local/experienced cerebral palsy management team) Coordinate assessment/plan with school programs Consider speech therapy, amplification, augmentative communication evaluation with experienced cerebral palsy management team 	<ul style="list-style-type: none"> School program*
VISION NORMAL	<ul style="list-style-type: none"> Assess per well-child practice guidelines 	
VISION ABNORMAL	<ul style="list-style-type: none"> New onset/changes: refer to ophthalmology (local/experienced cerebral palsy management team) Coordinate assessment/plan with school program 	<ul style="list-style-type: none"> Ophthalmology consult (local/experienced cerebral palsy management team)
Family Issues		
<ul style="list-style-type: none"> Review: Family transportation needs (van/lift) Ability to care for child (ADLs) Sleep issues for the adolescent and caregivers Sexual issues: birth control (male and female), exploration, dating, marriage (GYN Consult - local/experienced cerebral palsy management team) Career guidance/vocational Care providers/sitters are to be age/sex appropriate Long-term living arrangements: group homes, adult foster care, aging parents Continue explicit discussions and initiate plans for transition to adult health care. Assure family and adolescent consider need for complete or partial adult guardianship and complete process before 18th birthday. Prepare a summary of health care history to send to new PCP for adult care. Specific issues for the child and family: 		
<p>* Annual renewal of prescriptions for needed therapies. **Robert Palisano, Peter Rosenbaum, Doreen Bartlett, Michael Livingston, 2007 CanChild Centre for Childhood Disability Research, McMaster University http://motorgrowth.canchild.ca/en/GMFCS/resources/GMFCS-ER.pdf</p>		

Quick-Check Worksheet

NAME: _____

DOB: _____

MR #: _____

	WNL	Delay/Concern*	Referral/Tx*												
DATE															
Nutrition: Wt: Lt %ile															
OFC %ile															
*Feeding: Mechanism/Method															
Problem															
Pulmonary: Cold/Pneumonia															
RAD, Otitis/Sinusitis															
Hearing															
Vision															
Milestones: Gross Motor															
Fine Motor															
Communication															
Musculoskeletal: Hips															
Spine															
Other joints															
X-ray done															
Safety (age/dev. approp.)															
Social/Behavior: Child															
Parent															
Sibling/s															
School Program															
Equipment (w/c, power w/c, feeding pump, suction, walker, crutches, other)															
Splints/Braces (AFO, Hand, Back)															
Skin check															
Bowel/Bladder															
Medication review															
Lab check															

*Feeding Mechanism: PO/NG/Gt/Jt
 Problem: Vomit/Gag/Choke/Cough
 *Referral Options: PHN/Early Intervention Center/School/PT/OT/Speech/Psych/Specialist MD

Appendix: References and Resources

PROFESSIONAL READING LIST

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- King S, Teplicky R, King G, & Rosenbaum P. (2004) Family centered service for children with cerebral palsy and their families: a review of the literature [Review]. *Seminars in Pediatric Neurology*, 11, 78-86.
- Liptak G.S. (2005) Complementary and alternative therapies for cerebral palsy [Review]. *Mental Retardation & Developmental Disabilities Research Reviews*, 11, 156-163.
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- Morris C, & Bartlett D. (2004) Gross Motor Function Classification System: impact and utility [Review]. *Developmental Medicine & Child Neurology*, 46, 60-65.
- Nelson KB. (2002) The epidemiology of cerebral palsy in term infants [Review]. *Mental Retardation & Developmental Disabilities Research Reviews*, 8, 146-150.

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INFORMATION AND ORGANIZATIONS

American Academy for Cerebral Palsy and Developmental Medicine

www.aacpdm.org

Current articles and books about developmental disabilities for both professionals and families.

ARC of Washington State

www.arcwa.org

360-357-5596 or toll-free 888-754-8798

Advocates for the rights of citizens with disabilities.

Adolescent Health Transition Project

www.depts.washington.edu/healthtr

A resource for adolescents with special health care needs, chronic illnesses, physical or developmental disabilities.

Center for Children with Special Needs

www.cshcn.org

Information and resources for families who have children with special needs and for professionals that work with children with special needs.

Parent to Parent

www.arcwa.org/parent_to_parent.htm

800-821-5927

Find other parents with children with disabilities and support groups in your area.

United Cerebral Palsy

www.ucp.org

Information, legal issues, current political topics and links to relevant organizations.

United Cerebral Palsy of Oregon & Southwest Washington

www.ucpaorwa.org/
503-777-4166 or ucpa@ucpaorwa.org

Washington Parents Are Vital in Education (PAVE)

www.washingtonpave.org
wapave@wapave.org
800-572-7368
253-565-2266 (voice/TDD)

PERIODICALS

Exceptional Parent

www.eparent.com
877-372-7368

READING LIST FOR FAMILIES

BOOKS FOR ADULTS

Batshaw, Mark L. (2007). *Children with Disabilities*. Baltimore: P.H. Brooks.

Blank, Joseph. (1996). *Nineteen steps up the mountain: The story of the DeBolt family*. Albany, New York: Harrow & Heaton.

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Miller, F. and Bachrach, S. (2006). *Cerebral Palsy: A Complete Guide for Caregiving*. A Johns Hopkins Press Health Book

Turner, L., Lammi. B., Friesen, K, Phelan, N. (2001). *Backward Chaining: A Dressing Workbook for Parents*. CanChild Centre for Childhood Disability Research. www.canchild.ca/en/canchildresources/resources/chaining.pdf This dressing workbook is a helpful tool for parents and/or caregivers. It is a step-by-step guide on how to teach children dressing skills.

BOOKS FOR CHILDREN, AGES 4 TO 8

Anderson, Mary Elizabeth. (2000). *Taking Cerebral Palsy to School*. Plainview, New York: JayJo Books. ISBN: 1891383086

Debear, Kristen. (2001). *Be Quiet, Marina!* New York: Star Bright Books. ISBN: 1887734791

Heelan, Jamee. (2000). *Rolling Along: The Story of Taylor and His Wheelchair*. Atlanta, Georgia: Peachtree. ISBN: 156145219X

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