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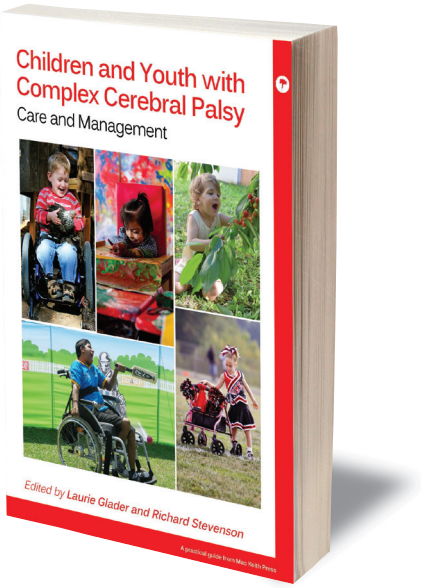
Practical Guide

Children and Youth with Complex Cerebral Palsy

Care and Management



Edited by **Laurie Glader** and **Richard Stevenson**

This is the first practical guide to explore management of the many medical comorbidities that children with complex CP face, including orthopaedics, mobility needs, cognition and sensory impairment, difficult behaviours, respiratory complications and nutrition, amongst others. Uniquely, it also includes contributions from children and parents, providing applied wisdom for family-centred care.

- Provides useful summary points of key recommendations at the end of each chapter.
- Includes Clinical Care Tools to guide clinicians in evaluation, preventive care and crisis management.
- Care Tools include a Medical Review Supplement, Equipment and Services Checklist and an ICF-Based Care: Goals and Management Form.

Nov. 2018 / 240 x 168mm / 404 pp / Softcover / ISBN 978-1-909962-98-9 / £39.95

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SAMPLE MATERIAL
From Chapter steoperosis and Fractures

Prevention

Nutrition

The main focus on preventing low bone density in this population is assuring the adequate intake of calcium, phosphorus, and vitamin D. There are other micronutrients that are important to bone health, such as zinc and magnesium, which may be deficient with severe malnutrition. The child on a regular diet will meet his phosphorus needs from meat, fish, eggs, and poultry. Calcium is primarily found in dairy products, though there are other good dietary sources of calcium, such as tofu, which can be added into blenderized tube feeds or smoothies (Table 6.1). For the child solely on G-tube feedings, both calcium and phosphorus intake should be evaluated. A quick way to calculate this is to read the label on the container for calcium and phosphorus content and multiply by the number of containers per day the child is getting. The goal is to meet the age-specific dietary reference intake (DRI) for those two minerals (Table 6.2). While the DRI for vitamin D is 600 IU from 1 to 70 years of age, serum levels should be obtained in order to maintain the level of 25-OH-vitamin D in the 'sufficient' range. The Endocrine Society has defined this as a level of 30 ng/mL or higher (Holick et al. 2011), whereas the most recent report from the Institute of Medicine (IOM) defined this as 20 ng/mL or higher, in a healthy population (IOM 2011). Because the non-ambulatory CP population is at high risk for low BMD, we recommend aiming for a level of 30–40 ng/mL. To achieve these levels, many patients will need supplements ranging between 1 000 to 8 000 IU daily, especially those who get little sun exposure (Table 6.3). The IOM report also recommended not exceeding serum levels of 50 ng/mL because of emerging evidence for potential adverse effects, especially at levels above 60 ng/mL. Checking a serum 25-OH-vitamin D level should be done annually beginning around age 3 years, and children with levels below 30 ng/mL should be supplemented with vitamin D.

Weight bearing: standers, gait trainers

As described earlier, lack of stress on the bone from lack of ambulation has a negative effect on BMD and bone morphology (Aguirre et al. 2006). It has been shown that weight-bearing exercise enhances bone mineral accrual in healthy children, particularly during early puberty (Hind and Burrows 2007). Weight bearing in standers and gait trainers is thought to provide several health benefits to children with CP such as improved gastro-intestinal motility, better lung function, increased bone density and improved socialization. However, only a positive effect on bone density and temporary reduction in spasticity has been demonstrated in reports of small numbers of patients in uncontrolled studies (Pin 2007). Well-controlled studies, especially in the non-ambulatory population, are needed (Paleg et al. 2014). On a practical note, positioning children with complex CP in standers can be challenging and few such children tolerate more than an hour a day in a stander. A pediatric physical therapist can best assess which type of stander (prone, supine, sit-to-stand) or gait trainer would be safest and most appropriate.

Table 6.1 Dietary sources of calcium

Dairy products: milk and yogurt	Serving size	Calcium (mg)
Milk, whole, 2%, 1%, skim, lactose-reduced, buttermilk, chocolate	8 oz.	316
Canned, evaporated with added Vitamin A and D	4 oz.	329–371
Milk, dry	¼ cup	377
Yogurt, plain, or flavored	6 oz.	258
Yogurt, fruit bottom	6 oz.	250
Yogurt, Greek, plain	6 oz	187
Yogurt, children's (eg: GoGurt)	1 tube	100
Yogurt smoothie, drinkable	3 oz.	100
Frozen yogurt	8 oz.	174
Ice cream	½ cup	84
Non-dairy beverages	**Serving size**	**Calcium (mg)**
Soy Milk, Silk	8 oz.	450
Orange juice (fortified with calcium and vitamin D)	4 oz.	175
Almond Milk, Almond Breeze	8 oz.	450
Soy-based foods	**Serving size**	**Calcium (mg)**
Tofu, firm/extra firm, in calcium	½ cup	250
Tofu, silken/regular, in calcium	1 slice	30
Soybeans, cooked	1 cups	260
Soybeans, roasted	1 cup	237
Meats, fish, and poultry products	**Serving size**	**Calcium (mg)**
Salmon, pink, canned	3 oz.	51
Sardines, pink, canned with bones	3 oz.	180
Legumes	**Serving size**	**Calcium (mg)**
White beans, cooked	1 cup	161
Navy beans	1 cup	126
Pinto beans, chickpeas	1 cup	79
Baked beans	1 cup	80–126

Table 6.1 (Continued)

Other	Serving size	Calcium (mg)
Brown sugar	1 cup	183
Blackstrap molasses	1 tbsp	200
Regular molasses	1 tbsp	41
Egg Custard	½ cup	150
Pancakes, made with milk	3 med.	150
Waffles (eg: Eggo)	1 ea.	132
Puddings, ready-to-eat	4 oz	54
Dairy products: Cheese	**Serving size**	**Calcium (mg)**
Cheese, soft: blue or feta	1 oz (30 g)	150
Cheese, hard: brick, cheddar, Colby, mozzarella, Swiss (includes lower-fat varieties)	1 oz	200–300
Cheese, processed spread	1 oz	130
Cheese, processed slices	1 slice	150
Cheese, grated parmesan	2 tbsp	110
Cheese, ricotta	½ cup	334
Cheese, cottage (1% or 2%)	2 cups	280
Cheese, cottage (nonfat)	2 cups	250
Macaroni and cheese (box mix)	1 cup	160
Fruits	**Serving size**	**Calcium (mg)**
Orange	1 med	60
Figs, dried	1 cup	241
Vegetables (measures for cooked vegetables)	**Serving size**	**Calcium (mg)**
Turnip Greens	½ cup	98.5
Bok choy/Chinese cabbage	½ cup	75
Kale, mustard greens	½ cup	165
Okra, frozen	½ cup	62
Broccoli	½ cup	31
Brussel sprouts	½ cup	28
Rutabaga, mashed	½ cup	21
Seaweed, raw: agar	½ cup	20

Table 6.1 (Continued)

Grain products	Serving size	Calcium (mg)
Oats, instant, enriched	1 pouch	100
Nuts and seeds	**Serving size**	**Calcium (mg)**
Almonds, dry roast	¼ cup	92
Almond butter	2 tbsp	112
Sesame Seeds, toasted kernels	¼ cup	42
Tahini	2 tbsp	130
Hazelnuts, chopped	¼ cup	32

Table 6.2 Dietary reference intake (DRI) for calcium and phosphorus

Age (years)	Calcium (mg)	Phosphorus (mg)
1–3	700	460
4–8	1000	500
9–18	1300	1250
19–50	1000	700
51–70	1000 males/1200 females	700

Table 6.3 Vitamin D intakes recommended for males and females by the Institute of Medicine (IOM) and the Endocrine Practice Guidelines Committee

Age (yr)	IOM recommendations for healthy populations[a]			Endocrine Society recommendations for patients at risk for vitamin D deficiency[b]	
	EAR	RDA	UL	Daily requirement (IU)	UL (IU)
1–3	400 IU (10 µg)	600 IU (15 µg)	2500 IU (63 µg)	600–1000	4000
4–8	400 IU (10 µg)	600 IU (15 µg)	3000 IU (75 µg)	600–1000	4000
9–13	400 IU (10 µg)	600 IU (15 µg)	4000 IU (100 µg)	600–1000	4000
14–18	400 IU (10 µg)	600 IU (15µg)	4000 IU (100 µg)	600–1000	4000
19–70	400 IU (10 µg)	600IU (15 µg)	4000 IU (100 µg)	1500–2000	10000

[a]IOM (2011); [b]Holick (2011)
EAR, estimated average requirement; RDA, Recommended Dietary Allowance; UL, tolerable upper intake level

Table 6.4 Bone Health Assessment Guide for the Primary Care Provider

Evaluate	When	How Often
Growth	Birth	Every well visit
Nutrition		
Feeding modality	Birth	Every well visit
Nutrient intake (in collaboration with dietitian)	2 years	Annually or with change in feeding modality
Medications	Birth	Every well visit
Weight Bearing Activities (in collaboration with PT)	2 years	Every well visit
Serum 25-OH-Vitamin D	3 years of age	Annually

Awareness of medications

As discussed above, certain medications can adversely affect bone density. Clinicians should consider these effects when evaluating drug choices and choose alternatives when possible. For instance, when starting birth control for a young woman with CP, there are many alternatives to depot medroxyprogesterone acetate, which is known to lower bone density even in a healthy, ambulatory population. Specific anti-convulsants, including phenobarbital, phenytoin and valproic acid, can cause decreased vitamin D levels (Kecskemethy and Harcke 2014). While there are many other anticonvuslants available, if a patient's seizures are well-controlled on one or more of these medications, an alternative is to continue their use while monitoring vitamin D levels more frequently and supplementing to maintain an appropriate level. Proton pump inhibitors are another class of medication that can adversely affect bone density, but alternatives are limited. If these drugs are used chronically, then obtaining a baseline DXA may be useful for later comparison.

Table 6.4 summarizes assessment and preventive measures for bone health in children with CP.

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November 018 / 404 40 x 168mm / o over ISBN 978-1-909962-98-9 / £39.95

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