

What Should I Do Now?

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Slide set adapted from those created by Laurie Glader, MD and Ellen Elias, MD

The Complex Child in Primary Care Tutor Guide

Case Materials:

Tutor's Guide
Case
Handouts: Introduction to Cerebral Palsy, MDs DD BASICS, The medical home
Slide Set
References

Evaluation Tools

Tutor's evaluation/prior to presentation
Tutor's evaluation/post presentation
Student evaluations

Objectives:

By the end of the session, learners will be able to:

1. To develop a problem list for a child with multiple medical problems
2. To prioritize family and physician goals for a child with multiple medical problems
3. To understand the definition and differential diagnosis of the term "Cerebral Palsy"
4. To understand the recognition and treatments of common complications of certain types of cerebral palsy
5. To identify impairments in different domains of function (posture and mobility, communication and cognition, feeding and nutrition, and social function and adaptation) in children with chronic conditions and to begin to address these impairments.

Overview of Complex Child Case:

Cerebral palsy is a common cause of childhood disability. In order to provide a "medical home" for the child with cerebral palsy, the primary care physician must be able to assess a child with complex needs and coordinate care among specialists and other agencies providing care for the child. An awareness of the associated medical conditions is needed to make appropriate referrals.

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This case presents the multiple challenges of caring for children with chronic conditions in a busy office practice. Primary care physicians often have difficulty integrating children with chronic conditions into office schedules and may not feel well trained to handle "high-severity," "low-prevalence" conditions. This has led to an over-arching system of care focused in hospitals, often with no general pediatric "coordinating" services. Poor immunization rates and a high prevalence of malnutrition are indicators that children with chronic conditions often lack adequate primary care. Returning to basic principles of developmental assessment and formulating written problem lists can help primary care physicians catalog, diagnose, and begin to manage these conditions more effectively.

This case presents the story of a 14-year-old boy who presents as a new primary care patient. Clinicians will learn how to provide an initial assessment, prioritize goals for care, and develop a treatment plan.

GUIDING QUESTIONS FOR DISCUSSION:

1. What should go on the problem list for this visit?
2. What other information historical information do you want?
3. What will you be looking for on physical exam?
4. What else can you add to the problem list?
5. Do you agree with the diagnosis of dystonic quadriplegic cerebral palsy?
6. How will you prioritize your concerns?
7. Which, if any, specialists would you involve?
8. What other resources could be helpful?
9. What factors may be contributing to malnutrition in Brian's case?
10. How should Brian's malnutrition be addressed?
11. Can Brian's motor function be improved?
12. Can Brian's communication abilities be improved?

GUIDING QUESTIONS AND DISCUSSION

1. What should go on the problem list for this visit?

Motor impairment
Dysarthria
Communication Impairment
Swallow dysfunction
Poor weight gain
Poor dentition
Educational setting may not be appropriate
Reactive airway disease
History of multiple pneumonias
Immunizations not up to date
Drooling
Constipation

It is very useful to create problem lists for children with multiple medical problems. Such a list can help the family and physician organize and prioritize their approach. Brian's complete history suggests several potential problems. He is not up to date on immunizations. Symptoms of upper respiratory infection, asthma and sleep disturbance may be due to aspiration of oral secretions and ingested food. Brian's difficulties with chewing, swallowing and drooling have led to prolonged mealtimes, protein calorie malnutrition, caries, chronic dehydration and stool impaction. His communication abilities may be far better than previously realized. This has limited his opportunities to interact and pursue interests if not limited occupational opportunities.

2. What other information historical information do you want?

Details of work up, in particular

--MRI/CT

--metabolic w/u

Delay in achieving milestones must be differentiated from loss of milestones. Risk factors for developmental impairment must be sought (prematurity, prenatal maternal illnesses or toxic exposures, family history of neonatal death or significant neonatal morbidity, CNS trauma).

Depending on the history and physical: chromosomal studies, central imaging, electroencephalography, detailed neurogenetic testing, screens for congenital infection, thyroid function testing or extensive social intervention may be indicated.

3. What will you be looking for on physical exam?

--presence of pathological reflexes

--cranial nerve exam

- motor exam
- range of motion of joints
- pain with motion or in any limbs
- general body habitus
- seating position in wheelchair
- skin exam
- back exam
- lung exam

Physical examination is helpful both to determine the appropriate diagnosis and to look for possible associated conditions and sequelae of cerebral palsy. On initial exam, it is important to determine the location of the dysfunction (upper motor neuron, lower motor neuron, neuromuscular junction, muscle fiber) and whether any syndromic dysmorphic features are present.

PART II

4. What else can you add to the problem list?

- poor dentition
- needs new wheelchair
- perineal irritation
- contractures
- scoliosis
- systolic murmur

This patient's physical examination reveals obvious indicators of malnutrition, dermatologic complications of inadequate bracing and positioning devices, and indications of chronic airway inflammation. This patient presents with several common associated complications of his neurologic dysfunction that must be addressed. These complications, left untreated, will add to the overall disability complex imposed by the primary condition (root cause). Malnutrition, swallowing dysfunction, immobility, joint contractures, unrecognized (undocumented) cognitive/communication strengths and isolation are common in this population. Primary caregivers should not assume that these joint contractures, unrecognized (undocumented) cognitive/communication strengths and isolation are inevitable in this population. Primary caregivers should not assume that these areas are addressed just because the patient receives care at an academic center. Physicians there often assume that these areas are addressed locally by physicians and schools.

5. Do you agree with the diagnosis of dystonic quadriplegic cerebral palsy?

Cerebral Palsy is a non-progressive disorder of posture and movement caused by a static upper motor neuron lesion. Upper motor neuron lesions produce hypertonicity (spasticity or dystonia), weakness, and hyperreflexia. Pyramidal (spastic) and extrapyramidal (dystonic, choreoathetotic, ataxic) and mixed types of cerebral palsy exist. Spastic cerebral palsy can be further subdivided into quadriplegia (four extremities), hemiplegia (two extremities plus or minus facial involvement on one side), and diplegia (both legs with little or no arm involvement). Because of the organization of the CNS, extrapyramidal types always occur as quadriplegia. Each type of Cerebral Palsy displays different rates of associated problems such as mental retardation, seizures, communication disorders.

Brian clearly has quadriplegia and his dystonic movements are consistent with a diagnosis of dystonic cerebral palsy.

Remember, children with neurogenetic and progressive motor impairments should not be considered to have cerebral palsy. This is the first important task of the physician primarily responsible for the care of the patient. The primary physician needs to ensure that someone (neurologist, geneticist or developmental specialist) has attempted to identify this root cause. By history, the subject of this case presented with failure to meet milestones. He has had an "adequate" evaluation to identify the root cause of his developmental dysfunction. Based on the specific type of cerebral palsy in this case (extrapyramidal), periodic metabolic or neurogenetic follow-up is indicated to try to identify this root cause as new information becomes available. Any loss of milestones is an immediate indication for evaluation.

6. How will you prioritize your concerns?

- family concerns
- immediate health threats
- referrals
- longer term issues

The family concerns must always be a high priority for children with multiple medical needs. To fully address all of Brian's needs is going to take a large investment of time and effort on the part of the family. Listening closely to the family and planning an approach that shows respect for their needs and family situation will create an environment in which the physician can work effectively with the family. Parents of children with complex medical needs very often of necessity become fierce advocates for their children. It is important to express your best "medical opinion" to the family and to state clearly what you feel are the most pressing medical issues. However, it is also important to recognize that they may not be willing or able to

implement every piece of advice. The number of specialist recommendations may quite literally be impossible to carry out so every day the family makes decisions about what they will and will not do. The physician who is able to take this comprehensive picture into consideration will be most likely to effectively work with the family.

7. Which, if any, specialists would you involve?

- dentist
- neurologist
- orthopedist
- speech/language – swallow study
- cognitive testing
- communication evaluation

Geneticists, neurologists, developmental/behavioral pediatricians and metabolism specialists can offer guidance with initial diagnosis of children with impaired development. Orthopedists and physical medicine specialists can help with screening, preventing, and treating secondary skeletal complications of cerebral palsy. Psychologists may help with cognitive testing, school placement and mental health issues. Social workers from early intervention programs, schools, and state agencies can help with community access and mental health issues. Speech and language pathologists can help with communication assessment and treatment as well as possible use of sophisticated communication devices.

8. What other resources could be helpful?

- school system (for younger child Early Intervention)
- SSI
- Medicaid (don't forget buy-in programs)
- DMR
- DPH
- State commissions for Blind, Deaf
- Parent support
- Family Voices
- KASA

All children with developmental impairments or significant risk of these impairments are eligible for rehabilitation services through Early Intervention programs from birth to age three. These same children are also eligible for cognitive, speech and rehabilitative services through their local school departments from age three to twenty-two. This is dictated by federal law. These children may be eligible for enhanced health insurance or disability income through the Social Security Administration. State departments of public health or mental retardation offer access to information, home health services and information networks. Several services (Mass. Network of

Information language pathologists can help with communication assessment and treatment as well as possible use of sophisticated communication devices. State agencies (Department of Public Health, Department of Mental Retardation) offer provider training for issues concerned with the care of Children with special healthcare needs. The American Academy of Pediatrics offers assistance with office material and training resources through their CATCH (Community Access to Child Health) and Medical Home programs. Do not assume that a patient's needs are being met by a single specialist or clinic at a tertiary medical center, previous primary physician, or school system. information concerning exercise and recreational opportunities for people with disabling conditions.

9. What factors may be contributing to malnutrition in Brian's case?

Many factors contribute to growth failure in cerebral palsy. By far the most common factor is inadequate caloric intake to meet altered energy requirements. Poor dentition, cranial nerve mediated chewing and swallowing dysfunction, aspiration of secretions or ingested food, gastroesophageal reflux or peptic ulcer disease, intestinal dysmotility, pain from constipation, and practical positioning factors during mealtime can all limit intake. Families may overestimate the time spent feeding children with cerebral palsy and overestimate ingested calories. Reported mealtimes in excess of thirty minutes are a documented risk factor for inadequate caloric intake. Children with spasticity who are mobile and children with extra-pyramidal cerebral palsy may require 150 to 200 % of recommended calories for age just to maintain weight due to the increased metabolic costs of movement. Children with profound spasticity and little or no movement may require less than 75 % of recommended calories to maintain weight. These children are at particular risk of calcium, vitamin and mineral deficiencies. Inadequate adaptive equipment can make feeding difficult or even dangerous by contributing to aspiration risk. Less common disorders of digestion (e.g. intestinal brush border enzyme deficiencies), and malabsorption syndromes are as likely in children with cerebral palsy as in the general population and should be considered.

10. How should Brian's malnutrition be addressed?

Dental referral and rehabilitation (under anesthesia if necessary) is indicated. A careful three-day diary of offered and ingested food and liquids or twenty four hour recall will give a good estimate of baseline calorie, fat, carbohydrate, protein, vitamin, and mineral intake. A history of malabsorption and food intolerance should be sought. Laboratory testing could include complete blood count (for anemia and neutropenia of malnutrition) and iron studies, serum calcium and albumin levels, vitamin D levels (especially if anticonvulsants have been taken). New adaptive equipment geared toward increasing head and trunk stability during mealtimes should be obtained. A speech therapy referral can help determine safe textures and temperatures of food to offer

based on the patients swallowing abilities. Videofluoroscopic swallow studies (modified barium swallow) and radionucleotide salivagrams can document aspiration risk which is often not clinically evident. Bulk softeners and cathartics can decrease abdominal pain due to stool impaction. Never use oral mineral oil in a patient of any age who lacks head and trunk control due to risk of aspiration and lipid pneumonia. Empiric treatment with antacids, H₂ blockers, promotility agents is sometimes indicated before more invasive testing is sought. An estimate of whether the patients caloric needs are depressed, increased, or greatly increased should be made. No current objective measure of caloric needs is clinically useful. High calorie supplements can be utilized and specific mineral and vitamin deficiencies should be corrected. Nasogastric feedings can be begun on a temporary basis. Gastrostomy with or without fundoplication should be considered if supplements will be required for more than six weeks or if aspiration risk is high. Goal weight for height is around 25%. Overweight is particularly difficult for people with motor impairments and increases the risk of immobility, skin breakdown etc.

11. Can Brian's motor function be improved?

No. In general movement patterns in children with cerebral palsy are stable after the age of five. Some increase in spasticity can be seen during times of rapid linear growth. Some increase in extrapyramidal symptoms is expected in late adolescence. Swallowing function, in particular, can deteriorate over time. Acquired orthopedic deformities imposed by spasticity can further limit movement over time. In the face of deteriorating function in any type of movement, other symptoms of neurologic change must be ruled out. A properly fitted wheelchair, proper braces, and modifications to the patient's environment can improve access to normal activities of daily living and improve his function in daily life. The primary physician must ensure that someone (physical therapist, rehabilitation specialist, orthopedist) is screening for secondary orthopedic causes of increased disability; utilizing physical therapy, exercise, and proper equipment to prevent their occurrence; and properly treating them when they arise.

13. Can Brian's communication abilities be improved?

Probably. There are many steps in a proper communication assessment and rehabilitation plan. First, visual and hearing ability must be carefully documented. Strabismus and amblyopia, refractive errors, retinal pathology, and cortical processing disorders and field cuts are all more common in children with cerebral palsy than in the general population. Global or frequency specific hearing loss must be treated where present. Careful non-verbal cognitive testing has not been done in this patient. Different types of receptive aphasia are possible in cerebral palsy and are addressed differently in speech therapy. Expressive aphasia must be differentiated from dysarthria. Access to sign, picture boards and at times sophisticated computer equipment can increase expressive communication abilities to age appropriate levels. At very least the primary physician must recognize that cognitive and communication abilities may be far ahead of a patient's motor abilities.

The Complex Child

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Part I

Brian is a fourteen year-old boy who presents for his first visit to your primary care office. He has moved from out of state and carries a diagnosis of “cerebral palsy.” You walk into the room and see a well-groomed adolescent boy seated in a manual wheelchair, laughing at his baby sister who is making faces at him from their mother’s lap. You begin the visit by asking Brian’s parents what their major concerns are for the visit. Brian's parents state that they are most worried about his growth and, "...would like something done about it." They also report they are concerned about school placement. After acknowledging these concerns, you go on to obtain the following history.

Brian was born at term after a “wonderful, easy” pregnancy with no complications at delivery. He failed to meet motor milestones in the first year. At fifteen months, he had poor head and trunk control. His mother says, “They’ve done every test in the book and they’ve never found anything. All they can tell me is he’s got C.P.” She tells you that he has had many episodes of pneumonia and is treated with albuterol for wheezing. He has had “lots” of orthopedic surgery. He has always been small and has gained “only a pound” in the past year. He needs assistance to eat and currently takes an hour to eat each meal of pureed table food with milk by spoon and by bottle. He has difficulty swallowing and gags and coughs frequently during feeding. He also has “constant” drooling and significant constipation.

His mother reports that Brian's motor abilities are extremely limited. He cannot completely control his head and cannot sit independently. Brian has a history of scoliosis and wears a soft "jacket" brace. His wheelchair is seven years old. Mrs. Smith tells you that “for years” Brian has been mainstreamed in the local public school. The other kids in his class were “great” and he always had kids taking him to ball games. His mother thinks he’s been getting PT, OT and speech therapy but does not know how he is performing academically and does not think he’s had any recent testing.

While Brian’s had multiple hospitalizations in the past, he has been fairly healthy over the last several years and has not been hospitalized for three years. His only medication is albuterol nebulizer treatments on an as needed basis. He has had no immunizations since infancy for no clear reason.

Brian can speak but is difficult to understand. You note that he appears to understand much of what you say to him. Brian's father reports that Brian enjoys watching baseball and hockey and that Brian reacts appropriately during games. Brian's attention span appears normal for age. Brian is able to gesture towards objects and looks up for "yes" and down for "no.”

The Complex Child

Part II

Amazingly, the office staff is able to locate the records from Brian's previous pediatrician who has prepared a detailed summary of his prior work-up. At the time of his presentation at 15 months he had a normal head CT, normal thyroid function tests, normal amino acids, and normal nerve conduction studies. A later MRI revealed mild lateral ventriculomegaly. Complete family history was non-contributory. There was no history of recurrent emesis, severe dehydration, serious intercurrent illnesses, hypoglycemia, or ketosis to suggest a metabolic disorder. There was no history of blood group incompatibility or jaundice suggesting kernicterus. Multiple consultations with child neurologists, geneticists, and metabolism specialists have not led to a unifying diagnosis. Brian was diagnosed with dystonic quadriplegic cerebral palsy as a matter of exclusion.

His surgeries have included bilateral derotational osteotomies of the hips at 8 years, hamstring, adductor, heel cord lengthening at 6 years and tonsillectomy and adenoidectomy at age 4. His weight 18 months prior to presentation is listed as 26.5 kg. His growth parameters have been persistently below the 5th percentile and his weight for height has fallen below the chart over the past 3 years.

On physical examination Brian appears to be alert and calm seated in his wheelchair. The brakes appear rusted and he appears uncomfortable in it. He is able to answer yes/no questions appropriately without failure. He is oriented to date, time and place. Length is 147 cm. Arm span is 150 cm. Weight is 27 Kg. Head circumference is normal (25 %). HEENT examination is remarkable for a normal head circumference and cranial shape. Brian's face is long and thin. He breathes through his mouth with poor dentition and malocclusion. Excessive calculus and mild caries are noted. Cranial nerve examination reveals bilateral facial diplegia and drooling. Some stridor is noted with differing head positions. Gaze is conjugate in all directions. Chest examination is clear with the exception of a systolic ejection murmur. There is a moderate scoliosis to the right. Abdominal examination reveals hard stool in the left lower quadrant. Extremity examination reveals fixed contractures of the hips and knees. Skin examination reveals chronic inflammation of the perineum. Neurologic examination reveals normal orientation to yes/no questions. Cranial nerve examination is noted above. Resting muscle tone is increased centrally and distally but is very variable with changes in position and excitement. No resting tremor is seen. A marked intention tremor is seen with volitional movement. Head control is incomplete. Brian cannot sit unsupported. He can reach toward objects but not grasp them. At times when he turns his head to the right, his right arm and leg extend uncontrollably. Deep tendon reflexes are increased with spreading to adjacent muscle groups. After the exam, you ask if Brian understands "more than some people think he does", his parents said that they "had wondered if he could communicate better but thought that he could not because they were told that he was 'retarded.'"

The Complex Child

Epilogue

You administer tetanus, measles mumps rubella, polio boosters and influenza vaccine according to standards of routine healthcare and begin a Hepatitis B series. You place a PPD. You obtain a complete blood count, serum calcium and albumin levels to begin to assess Brian's nutrition.

Brian was referred to a local dentist who successfully cleaned his teeth without anesthesia. However, anesthesia will be required to fully correct decay and malocclusion. A three-day diary and nutrition consultation revealed inadequate calorie and calcium intake. You began oral supplementation with 35 Kcal/oz formula covered under prior approval from Medicaid and a calcium containing antacid. A speech therapy evaluation revealed safe swallowing with thickened liquids and purees, but aspiration with thin liquids and crunchy solids. The speech therapist is helping the family alter meal preparation to offer these textures. You will check on weight gain in monthly intervals and are hoping for a twice-normal weight gain velocity for age over a six month period. An orthopedist and physical therapist are ordering proper braces and seating devices to enhance positioning during mealtimes and eventually during communication training sessions. An orthopedist and physical therapist are ordering proper braces and seating devices to enhance positioning during mealtimes and eventually during communication training sessions. You obtained a contact number for an augmentative communication center in a bordering state from Exceptional Parent Magazine and an internet search on the World Wide Web and plan to encourage the parents to attend. You learn that a hearing test and visual field testing is necessary before an appointment is scheduled. Cognitive testing will be done at the first session.

You find on further questioning that the family is concerned about Brian's sixteen year old sister who is spending less and less time at home and refusing to have friends visit her at home. A second appointment is made for her.

Handout #1 - CEREBRAL PALSY

Definition: Cerebral palsy (CP) represents a spectrum of neurodevelopmental syndromes due to a non-progressive insult to the developing brain that may manifest as deficits in the motor, cognitive, sensory, and other areas. Though the underlying insult is static, the presentation may change over time.

Incidence: 2-3/1000 live births (about 1/2 are premature)

Prevalence: 100,000 patients under 18 years in US

Annual cost: \$5 billion per year (199? \$'s)

Survival: 30-year survival 87%

TYPES OF CP

(1) Spastic or “pyramidal” Cerebral Palsy (65% of all CP) is due to an upper motor neuron defect and so presents with increased tone, clasp-knife, increased deep-tendon reflexes, pathological reflexes and spastic weakness.

Spastic Cerebral Palsy is further divided topologically by the limbs most affected.

- *Hemiplegia*: (30%): one side of the body; arm generally affected more than leg.
- *Quadriplegia*: (5%): all limbs affected; legs more affected than arms
- *Diplegia* (30%): lower extremities more involved than upper extremities
- *Double hemiplegia*: all 4 extremities, upper extremities more involved than lower
- *Monoplegia*: one extremity, usually upper
- *Triplegia*: One upper, two lowers; either hemi+di, or variant of quad

(2) Dyskinetic Cerebral Palsy (19% of all CP) generally involves the basal ganglia and is characterized by involuntary movements, and fluctuating muscle tone. Tone is often lower (even hypotonic) when the child is sleeping. Tone also varies while awake.

Dyskinetic Cerebral Palsy is further divided by type of movement difficulty into:

- *Athetoid*: characterized by chorea (random, jerky motions) and athetosis (slow, writhing movements often involving face and arms)
- *Dystonic*: characterized by rigid posturing of trunk and head

(3) Ataxic Cerebral Palsy involves injury to the cerebellum and is characterized by difficulty in balance and positioning the body in space.

(4) Mixed Cerebral Palsy

Etiology: It is important to always look for a cause since it is not uncommon for other neurological disorders (e.g., Smith-Lemli-Opitz syndrome, spinal cord disorders or chromosomal abnormalities) to initially be diagnosed as cerebral palsy. However, the etiology of CP often is difficult to determine. Historically, birth injury was often blamed, but birth injury causes only 8-12% of CP

In term babies the cause is generally prenatal defect or insult

In premature babies the cause may be pre- or peri-natal

Common Causes of CP in Preterm Infants

- 1) **Periventricular Hemorrhagic Infarction:** Large, primarily unilateral hemorrhage in periventricular white matter. Clinically common symptoms include hemiparesis, lower extremity > upper extremity predominantly involved + intellectual deficits. **Incidence is decreasing.**
- 2) **Periventricular Leukomalacia:** In contrast, incidence of PVL is not decreasing. It presents with bilateral, symmetric, non-hemorrhagic lesion in PVL. Clinically: “spastic

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diplegia” weakening of all extremities but lower>upper. Intellectual deficits in 25-50% may be related to more diffuse white matter injury.

Common Causes of CP in Term Infants

- 1) Hypoxic Ischemic Encephalopathy: 12-24% of term infants with CP.
- 2) Vascular lesion (venous preterm, arterial in term) presents 4-9 mo of age. Cause 90% of Hemiplegias
- 3) Brain Malformations – Cause the remaining 10% of Hemiplegias

Management:

- 1) Improve functional status: think school, home, mobility, communication
- 2) Help parents
- 3) Coordinate issues

Associated problems: -

- Feeding
- Ortho (increased tone, contractures, scoliosis)
- Respiratory
- GI (esp. reflux and constipation)
- Sensory (hearing, vision)
- Communication
- Seizures
- MR, learning disabilities

Referrals:

- Ortho: Anyone with decreased range of motion, functional impairment.
- Physiatry: to assess function and for spasticity management
- Neurology: for diagnosis, seizure management, etc.
- GI: for issues such as reflux, dysphagia, constipation, etc.
- (see attached list of other specialtie

Oral Medications:

Baclofen (Lioresal): A GABA analog inhibits spinal mono and polysynaptic reflexes.

Diazepam (Valium): Valium works in CNS to enhance inhibitory GABA effects.

Clonazepam (Klonopin): Similar effects to valium.

Dantrium Sodium (Dantorlene): Acts directly on skeletal muscle.

Tizanidine (Zanaflex): Approved in 1996 for adults.

Nerve and Muscle Blocks:

- **BOTOX (botulinum type A toxin):** Inhibits acetylcholine release at the neuromuscular junction making the muscle weaker temporarily.
- **Phenol injections:** Injected around “motor point” where nerve branch enters muscle. Causes demylenation which lasts 4-12 months.

Therapeutic Electrical Stimulation (TES): Electrodes deliver low level electrical stimulation during the night to weak and non-spastic antagonist muscles. A growth in muscle bulk, decreased tone and hyperreflexia, and improved function can be seen.

Intrathecal Baclofen Pump: Much smaller doses can be used intrathecally to get good effects without as many side effects. Dosing can be adjusted non-invasively.

Dorsal rhizotomy: Selective and permanent disruption of 1-alpha afferent input to the cord. Results are variable and best used in carefully selected patients (pure spasticity, adequate trunk and leg strength, age 3-8, spontaneous forward locomotion, absent primitive reflexes, adequate cognitive skills, social factors).

Module Evaluation

For presenters to fill out before the teaching session

A. I consider myself

- | | | | | |
|---|--|--|--|--------------------|
| 1. A nationally known expert on this topic | 2. A locally known expert on this topic | 3. Very knowledgeable on this topic | 4. to have learned about this topic to teach it | 5. Not sure |
|---|--|--|--|--------------------|

B. I spent approximately _____ minutes preparing for teaching this topic.

C. Of the time I spent preparing to teach this topic, I used material provided to me as part of the Serving the Underserved Curriculum

1. 100% of the time
2. 75-99% of the time
3. 50-74% of the time
4. 25-49% of the time
5. <25% of the time

D. How appropriate were the educational objectives?

- | | | | | |
|---------------------|----------------|-------------------|----------------|--------------------|
| 1. Excellent | 2. Good | 3. Average | 4. Poor | 5. Not sure |
|---------------------|----------------|-------------------|----------------|--------------------|

E. How appropriate were the tutor notes?

- | | | | | |
|---------------------|----------------|-------------------|----------------|--------------------|
| 1. Excellent | 2. Good | 3. Average | 4. Poor | 5. Not sure |
|---------------------|----------------|-------------------|----------------|--------------------|

F. How appropriate were the references?

- | | | | | |
|---------------------|----------------|-------------------|----------------|--------------------|
| 1. Excellent | 2. Good | 3. Average | 4. Poor | 5. Not sure |
|---------------------|----------------|-------------------|----------------|--------------------|

G. If your answer to any of the above questions (except A) was 3, 4 or 5, please comment.

Please feel free to write further comments on the back of this sheet.

Thank you for taking the time to fill out this evaluation.

*This material was adapted from that created by Janet Hafler, Ed.D.

Module Evaluation

(For Presenters to use after the teaching session)

Presenter: _____

Your responses will help us refine and develop this case.

A. Please rate the overall quality of this material as a stimulus for learning.

1. **Excellent** 2. **Good** 3. **Average** 4. **Poor** 5. **Not sure**

B. Please rate the classes participation in the learning

1. **Excellent** 2. **Good** 3. **Average** 4. **Poor** 5. **Not sure**

C. How comfortable were you with case based teaching

		Not at All			Very Much	
1.	Prior to this teaching session	1	2	3	4	5
2.	During the teaching session	1	2	3	4	5
3.	After the teaching session	1	2	3	4	5

D. Please list how long you spent on this topic, and how the time was divided

Total Time _____ **minutes**

Time spent on case discussion _____ **minutes**

Please describe how you spent the rest of the time

E. Please Rate each of the following

		Poor			Excellent	
1.	The Educational Objectives	1	2	3	4	5
2.	The Case Vignette	1	2	3	4	5
3.	The Tutor Guide, including guiding questions	1	2	3	4	5
4.	Reference List	1	2	3	4	5
5.	Handouts	1	2	3	4	5
6.	Audiovisual Materials	1	2	3	4	5

If you answered 1-3 on any of the above, please comment further

- F What were the cases strengths
- 1.
 - 2.
 - 3.

- G What were the cases weaknesses
- 1.
 - 2.
 - 3.



What Should I Do Now?

H What is the single most important thing that you learned from the case discussion?

I Case Evaluations

1. Do you think facts or data should be added? **1. Yes** **2. No**
If **yes**, what should be added?

2. Do you think facts or data should be deleted? **1. Yes** **2. No**
If **yes**, what should be deleted?

J. Tutor notes evaluation

1. Did you use the **tutor notes**? **1. Yes** **2. No**
If **no**, why not?

2. What were the **tutor notes** strengths? 1.

2.

3.

3. What were the **tutor notes** weaknesses? 1.

2.

3.

4. How would you suggest improving the **tutor notes**?

5. Do you think facts or data should be added to the **tutor notes**? **1. Yes** **2. No**

If **yes**, what should be added?

6. Do you think facts or data should be deleted from the **tutor notes**? **1. Yes** **2. No**

If **yes**, what should be deleted?

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K Slide Evaluation

1. Did you use any of the **slides**? **1. Yes** **2. No**
If yes, which ones
2. How would you suggest improving the **slides**?
3. Do you think more slides would be useful? **1. Yes** **2. No**
If **yes**, what should be added?
4. Do you think there are slides that will never be **1. Yes** **2. No**
useful?
If **yes**, what should be deleted?

- L Did you use any other materials **1. Yes** **2. No**
If **yes**, what other materials?

If supplied by the Serving the Underserved
Project, how would you improve the material

M. What did you as a teacher learn about this topic?

- #1
- #2
- #3

Please feel free to write any further comments on the back of this form

Thank you for taking the time to fill out this evaluation.

*This material was adapted from that created by Janet Hafler, Ed.D.

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What Should I Do Now?

Module Evaluation

Presenter: _____

Your responses will help us refine and develop this educational material. The person completing this form is:

PGY1 PGY2 PGY3 Fellow Faculty Other _____

A. What is the single most important thing you learned from the case discussion today.

B. Please rate the overall quality of this case as a stimulus for learning.

1. **Excellent** 2. **Good** 3. **Average** 4. **Fair** 5. **Poor**

C. The facilitator

		Not at All			Very Much		
1.	Encourages student direction of teaching	1	2	3	4	5	
2.	Stimulated interest in the subject matter	1	2	3	4	5	
3.	Encouraged Group Participation	1	2	3	4	5	

D. I consider the facilitator

1. A nationally known expert on this topic 2. A locally known expert on this topic 3. Very knowledgeable on this topic 4. a teacher who learned about this topic to teach it 5. **Not sure**

E. Please rate each of the following components of the teaching session (N/A for not applicable)

		Poor		Good		Excellent	
1.	Case Vignette	1	2	3	4	5	N/A
2.	Case Based/Learner Centered Format	1	2	3	4	5	N/A
3.	Handouts/Supplemental Materials	1	2	3	4	5	N/A
4.	Teacher/Facilitator	1	2	3	4	5	N/A

F. Do you think information should be added? 1. **Yes** 2. **No** 3. **Not Sure**
If **yes**, what should be added?

G. Do you think information should be deleted? 1. **Yes** 2. **No** 3. **Not Sure**
If **yes**, what should be deleted?

H. Comments

Please feel free to write any comments on the back of this sheet.

Thank you for taking the time to fill out this evaluation.
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REFERENCES

Capute, Arnold J. and Accardo, Pasquale J. "Cerebral Palsy: The Spectrum of Motor Dysfunction" in Arnold J. Capute and Pasquale J. Accardo, eds. *Developmental Disabilities in Infancy and Childhood, 2nd Edition Volume II: The Spectrum of Developmental Disabilities*. Paul H. Brookes Publishing Co. Baltimore, 1996.

Dormans, John P. and Pellegrino, Louis *Caring for Children with Cerebral Palsy: A Team Approach*. Paul H. Brooks Publishing Co. Baltimore, 1998.

du Plessis AJ, Volpe JJ Perinatal brain injury in the preterm and term newborn. *Curr Opin Neurol* 2002 Apr;15(2):151-7

Leonard, Jane Faulkner, Cadenhead, Sherri L., and Myers, Margaret. *Keys to Parenting a Child with Cerebral Palsy*. Barron's Hauppauge, NY, 1997.

Pellegrino, Louis "Cerebral Palsy" in pp499-528 in Mark L. Batshaw, ed. *Children with Disabilities*, 4th Edition. Paul H. Brookes Publishing Co. Baltimore, 1997.

Sulkes SB MD's DD BASICS: identifying common problems and preventing secondary disabilities. *Pediatr Ann* 1995 May;24(5):245-8, 251-2, 254