WHAT DO WE DO NOW? OUR CHILD HAS CP????

DEVELOPMENTAL, MEDICAL, EDUCATIONAL, SOCIAL & EDUCATIONAL ASPECTS OF CP

BARBARA M. WEISSMAN, MD

Disclaimer: The content is for personal use and not to be redistributed
DISCLOSURES

• NO FINANCIAL DISCLOSURES
• NO INDUSTRIAL RELATIONSHIPS
GOALS OF PRESENTATION

• Address Concerns of Families with a CP diagnosis
• Understand Developmental issues associated with the Diagnosis of CP
• Address Key Medical issues impacting CP
• Understand Educational Issues Associated with the Diagnosis of CP
• Understand Social Issues Associated with the Diagnosis of CP
• Understand the Emotional Aspects Associated with the Diagnosis of CP
Addressing the Diagnosis of CP

• Be clear about the differential
• Describe the definition
• Use the GMFS and engage the family in using the GMFCS
• Be clear the level is not static
• Be clear that the definition does not define cognition
<table>
<thead>
<tr>
<th>nl</th>
<th>Findings</th>
<th>Pertinent Physical Finding</th>
</tr>
</thead>
<tbody>
<tr>
<td>GENERAL</td>
<td>ALERT INTERACTIVE</td>
<td>Left sided weakness with reflexes brisker on left than the right</td>
</tr>
<tr>
<td>HEAD</td>
<td>NORMOCEPHALIC</td>
<td>Left central facial</td>
</tr>
<tr>
<td>ENT</td>
<td>MOIST MUCOUS MEMBRANES, CLEAR CONJUNCTIVAE</td>
<td></td>
</tr>
<tr>
<td>NECK</td>
<td>NO ADENOPATHY, FULL RANGE OF MOTION</td>
<td></td>
</tr>
<tr>
<td>CHEST</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CARDIAC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ABDOMEN</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SKIN</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MENTAL STATUS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CRANIAL NERVES</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MOTOR</td>
<td>CLEAR TO AUSCULTATION BILATERALLY, NO WHEEZES, GOOD AIR ENTRY</td>
<td></td>
</tr>
<tr>
<td>SENSATION</td>
<td>SOFT. NON-TENDER. NO HSM</td>
<td></td>
</tr>
<tr>
<td>DEEP TENDON REFLEXES</td>
<td>NO LESIONS</td>
<td></td>
</tr>
<tr>
<td>COORDINATION</td>
<td>ALERTMotor Function: Level 2- Infants maintain floor sitting but may need to use their hands for support to maintain balance. Infants creep on their stomach or crawl on their hands and knees. Infants may pull to</td>
<td></td>
</tr>
<tr>
<td>GAIT</td>
<td>PERRL, NORMAL FUNDI, EOM FULL, NORMAL FACIAL MOVEMENT AND SENSATION. NORMAL HEARING. PALATE AND TONGUE MIDLINE. NORMAL SHOULDER SHRUG.</td>
<td></td>
</tr>
</tbody>
</table>

Ashworth/Gross Motor Function Scoring: 2 Gross stand and take steps holding onto furniture
Addressing the Diagnosis of CP

• Early on help families with RESOURCES
• Good Sources of Information – AACPDM, NIH, CP Foundation
• Parent SUPPORT – Parent to Parent, FOCUS, UCP
• Equipment Help – FODAC, Special Needs Kids (Adaptive Lending Library)
• Other Therapies – Lekotek, Hippo therapy, CVI, GA PINES, other therapies
YOUR CHILD HAS JUST BEEN DIAGNOSED WITH CP

• Your child is the same person before receiving the diagnosis as he or she is after receiving the diagnosis

• Your child is STILL your pride and joy

• YOU are STILL the parent
Development of the Child with CP

• Important that the child not be compared to siblings for developmental progress
• However, important to seek early intervention services
• Important to engage the family in a positive manner
• Siblings still need attention!
ORGANIZE THE CARE EARLY

• Consider the Medical “Home” for your child
• Seek out Early Intervention Services
• Seek out any additional Services that will help your child and your family
• Keep a Binder/log book /computer file
HOW TO MAXIMIZE THE CHILD’S DEVELOPMENT

• Early Intervention and NO WAITING
• Do NOT WAIT with BCW
• The parent needs to learn as much as possible about the child’s CP and developmental stage
• SEEK out care to maximize progress
  – GI/Speech for FEEDING
  – PT/Orthopedics for motor control care
Address Issues Impacting Developmental Progress

• Address other associated conditions
• Ensure that the child is HEARING properly
• Ensure that the child’s vision has been thoroughly evaluated
• Address any associated Neurological conditions – example EPILEPSY
• Address SLEEP difficulties
• Do not forget the importance of feeding and nutrition
HEARING and CP

- Hearing difficulties of various causes can be present in up to 1/3 children with CP
- Severe Hearing impairment impacts 5% of children
- Impact on language development key
- Early identification key for best outcome
VISION and CP

- Children may have ocular motility problems
- They may also have refractive errors
- Children with CP may also have cortical visual impairment
- Of these children 10% have significant involvement
- Need to identify problems early for early intervention
Epilepsy and CP

• Up to 50% of children with CP may have seizures
• Some of the seizure types may be subtle
• Need to recognize seizures to treat appropriately
• If seizures are untreated control may become more difficult over time
SLEEP and CP

- Up to 40% of children with CP have sleep difficulties
- Frequently these problems are related to pain and spasms
- Difficulty with reflux/GI problems at night
- Different impact of sound and light at night
- Impact of nocturnal seizures
Nutritional Issues and CP

- Early on good nutrition key for brain growth
- Logarithmic growth early - critical period
Nutritional Issues & CP

• Children may have dysphagia
  – Difficulty with chewing and swallowing food
• Gastro-esophageal Reflux
  – Eating may be quite painful
• Difficulty advancing diet due to textures
• Difficulty with self feeding skills due to motor limitations
• Constipation
Nutritional Issues & CP

• Address Dysphagia – evaluate with ST evaluation – may need OPMS
  – Oral motor control issues with drooling
• May need GT for adequate calories and fluid
• Feeding programs for advancing diet – for issues with textures and issues with chewing
  – Feeding programs with ST and OT assistance
Nutrition & CP

• Gastroesophageal Reflux
  – May need the help of a GI for appropriate medical management
  – May need surgical management

  o The GI may help with constipation issues
    o Medical management
    o Assisting with adequate fluid management
    o Important to control since major impact on spasticity
Bristol Stool Chart

Type 1: Separate hard lumps, like nuts (hard to pass)
Type 2: Sausage-shaped but lumpy
Type 3: Like a sausage but with cracks on the surface
Type 4: Like a sausage or snake, smooth and soft
Type 5: Soft blobs with clear-cut edges
Type 6: Fluffy pieces with ragged edges, a mushy stool
Type 7: Watery, no solid pieces. Entirely Liquid
Toileting may be difficult – may need help with reinforcements &/or adaptive equipment
Educational Issues & CP

• EARLY INTERVENTION
• Theoretically early referrals with BCW
• Theory often does not match practice
• Varies from County to County
• Resources vary from County to County
Educational Services & CP

• Educational Services are MANDATED
• Individuals with Disabilities Education Act (IDEA) – mandate for individuals with disabilities from birth to 21 years
• “Free appropriate public education”
• Parent Training and Information Center – each state has one that is federally funded
Good Education Resources for Families & the CP Child

• Department of Education’s IDEA Site
• Parent’s Guide to Developing Your Child’s IEP – Center for Parent Information Resources
• Family Center on Technology and Disability -The National Center on Dispute Resolution in Special Education
ISSUES and the IEP

- Appropriate evaluation of the child
- Appropriate resources – use the technology the child is using
- Mobility of the Child – use of devices – walker, gait trainer, crutches, stander
- Consideration of other impairments – vision services, hearing modifications
Educational Concerns & CP

- Attention – often issues with short span
- Motor planning difficulty – organization and sequencing of movement
- Perceptual difficulties and language difficulties
- Difficulty with fine and gross motor control – fatigue readily
Social Issues & CP

• 25% of Children with CP have behavioral issues
• Greatest risk: intellectual disability, epilepsy, severe pain or milder level physical disability
• Problem behaviors: hyperactive, anxious, prone to conflict, obstinate or antisocial behaviors
Social Issues & CP

• Teenagers and Adults with CP prone to Depression and Anxiety
• Cognitive behavior therapy (CBT) for anxiety
• Need appropriate resources for Depression
Emotional Concerns for CP

• Engage in healthy activities
  – Swimming – Fast Fins Adapted Swim Team
  – Blaze Sports
  – Dance- Newnan School of Dance
  – Baseball – Challenger Baseball League
  – Cheerleading – Chattooga Gymnastics

• Maximize communication systems

• Inclusion programs
Issues with Transition to Adulthood

• Bullying in Middle School
  – Often caregivers and school unaware
  – Major blow to self-esteem
• Transition to Independent Living
  – ADLs and Gross/fine motor functioning
• Appropriate Secondary Education/Training
• Adolescents with CP participate in fewer social activities
Transition to Adulthood

- At most 20% of people with a disability in the workforce
- This compares to 80% without a disability
- The US Office on Disability Employment Policy (ODEP) - source of information on employment & disability
  - Develops & influences use of evidence-based disability employment policies & practices
Resources

• Cerebral Palsy Information Page NIH

• Cerebral Palsy CDC

• Cerebral Palsy Foundation
  – http://yourcpf.org

• United Cerebral Palsy – UCP Georgia
  – http://ucp.org
  – http://ucpga.org
QUESTIONS