



CEREBRAL PALSY



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CEREBRAL PALSY

Learning Objectives

1. Understand the diverse nature of Cerebral Palsy (CP)
2. Recognize the impact this has on the patient and the family
3. Understand that many children and adults with CP have normal intelligence and lead productive lives
4. Appreciate the diversity of causes of CP
5. Understand the importance of early identification and treatment
6. Know that CP requires team management and that we (UCH) are part of the team.
7. Have an exposure to the treatments of CP
8. Be aware of the laws that protect people with disabilities
9. Understand there are risks from COVID-19 for patients with CP



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What is Cerebral Palsy (CP)?

What is Cerebral Palsy (CP)?

- CP is an impairment of the brain
- The area of the brain impaired determines how CP presents
- The severity of CP relates to the severity of the impairment of the brain tissue
- Cerebral Palsy is non-progressive
 - The original injury does not continually get worse
 - However, the presentation and symptoms may change as the child grows and matures



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What is Cerebral Palsy (CP)?



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What is Cerebral Palsy (CP)?

Cerebral palsy refers to a group of neurological disorders that appear in infancy or early childhood and permanently affect body movement and muscle coordination

Cerebral Palsy NIH

National Institute of Neurological Disorders and Stroke



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What is Cerebral Palsy (CP)?

- There are many causes of brain impairment
 - Genetic
 - Brain malformation
 - Not genetic
 - Toxicity (Rio Grande; BROWNSVILLE, Texas - In 1991-1992; Link in Take Home)
 - Happen in the womb
 - Bleeding in the brain
 - Lack of Oxygen



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What is Cerebral Palsy (CP)?

- There are many causes of brain impairment
 - Prematurity
 - During birth
 - Birth Asphyxia (hypoxia)
 - Birth Trauma
 - During growth
 - Accidents
 - Infection
 - Malnutrition
 - After maturity
 - Accidents
 - Drugs



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What is Cerebral Palsy (CP)?

- The impairment may be
 - Mild
 - Moderate
 - Severe



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How does CP Present?

- Muscle control problems
 - Weakness (Hypotonia)
 - Tight muscles/stiffness (Spasticity/Hypertonia)
 - Coordination
 - Clumsiness
 - Abnormal reflexes
 - Overactive
 - Absent or weak



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How does CP Present?

- Different parts of the body or brain may not be affected equally
 - Hemiplegia
 - Only the left or right side
 - Quadriplegia
 - All extremities
 - Diplegia
 - Affects the same body parts on each side of the body



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How does CP Present?

- Dyskinetic
 - Spontaneous unusual movements (athetosis)
- Ataxic cerebral palsy
 - Balance problems



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How does CP Present?

- 80% of patients will have spastic clinical features
- 10-20% of patients will be the Dyskinetic type
- 5-10% will have Balance problems



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How does CP Present?

- Associated problems
 - Intellectual Disability
 - Thinking or problem solving
 - Social interaction
 - Irritability
 - Learning problems
 - **Many have normal intelligence**



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How does CP Present?

- Associated problems
 - Seizures
 - Vision problems
 - Hearing problems
 - Autism



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How does CP Present?

- Secondary Problems
 - These are a result of the previous problems listed



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How does CP Present?

- Secondary Problems
 - Distorted limbs or scoliosis
 - Imbalance of muscle tone



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How does CP Present?

- Dental problems
 - Poor hygiene
 - Constant biting or grinding
 - Poor dentition: genetics



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How does CP Present?

- Secondary Problems
 - Problem with spatial awareness
 - Proprioception-where their limbs are in space
 - Where they are in relation to people or objects
 - Orientation in 3-dimensional space



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How does CP Present?

- Secondary Problems
 - Hypertonia, Hypotonia cause
 - Joint problems
 - Unusual posturing/distortions
 - Swallowing, Breathing problems
 - Communication difficulties



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How does CP Present?

- Why are CP, associated problems, and secondary problems all grouped together?
- When a negative event or insult occurs
 - Affects the entire brain
 - Some parts of the brain are more sensitive than others
 - Affects the entire body



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How does CP Present?

- Why are CP, associated problems, and secondary problems all grouped together?
 - Think about **genetic problems** and **prematurity**
 - Genetic Syndromes
 - Altered brain structure and heart disease
 - Prematurity
 - Brain injury/hypoxia and GI problems (NEC)



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How Do We Identify Cerebral Palsy (CP)?

How Do We Identify Cerebral Palsy (CP)?

- Early diagnosis is very important
- Early treatment can reduce the impact of what has damaged the brain
- Early treatment can reduce the impact of what has damaged the other body parts
- Early support for the family reduces stress



How Do We Identify Cerebral Palsy (CP)?

- What Early Signs To Look For:
 - Infant Less than 6 months of age
 - Head lags when you pick him up while he's lying on his back
 - Feels stiff
 - Feels floppy
 - When picked up
 - Legs get stiff
 - Legs cross or scissor



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- What Early Signs To Look For:
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How Do We Identify Cerebral Palsy (CP)?



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How Do We Identify Cerebral Palsy (CP)?



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How Do We Identify Cerebral Palsy (CP)?

- What Early Signs To Look For:
 - Infant older than 6 months of age
 - Doesn't roll over in either direction
 - Cannot bring hands together
 - Have difficulty bringing hands to mouth



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How Do We Identify Cerebral Palsy (CP)?

- What Early Signs To Look For:
 - Reaches out with only one hand while keeping the other fist



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How Do We Identify Cerebral Palsy (CP)?



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How Do We Identify Cerebral Palsy (CP)?

- What Early Signs To Look For:
 - Baby older than 10 months of age
 - Crawls in a lopsided manner,
 - pushing off with one hand and leg while dragging the opposite hand and leg
 - cannot stand holding onto support



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How Do We Identify Cerebral Palsy (CP)?

- Steps to early diagnosis
 - Developmental Monitoring
 - Developmental Screening
 - Developmental and Medical Evaluations



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How Do We Identify Cerebral Palsy (CP)?

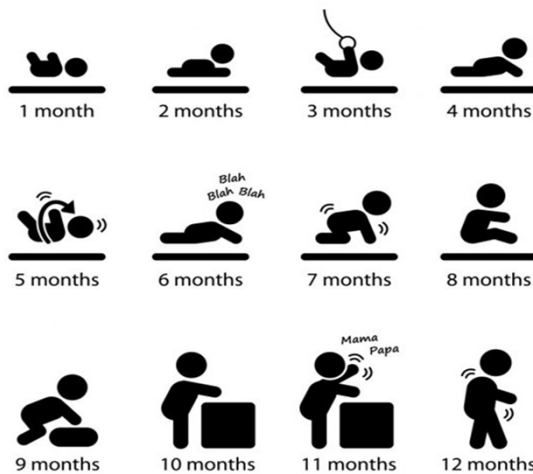
- Steps to early diagnosis
 - Developmental Monitoring
 - also called surveillance
 - tracking a child's growth and development over time
 - Reviewing the history



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How Do We Identify Cerebral Palsy (CP)?



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How Do We Identify Cerebral Palsy (CP)?

- Steps to early diagnosis
 - Developmental Screening
 - a short test for developmental delays
 - Example: CDC's Developmental Milestones
 - Links in the TAKE HOME SHEET for this and other tools



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How Do We Identify Cerebral Palsy (CP)?

- Steps to early diagnosis
 - Developmental Screening
 - AAP recommends screening
 - 9 months
 - 18 months
 - 24 or 30 months
 - Any time a parent has questions about a child's development



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How Do We Identify Cerebral Palsy (CP)?

- Steps to early diagnosis
 - Developmental Screening
 - Early Childhood Intervention (ECI)
 - Statewide program in Texas
 - Under the Texas Health and Human Services Commission
 - Children birth to age 3 years
 - They provide testing and treatment
 - There are criteria to receive services



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How Do We Identify Cerebral Palsy (CP)?

- Steps to early diagnosis
 - Developmental and Medical Evaluations
 - Goal of a developmental evaluation
 - To diagnose the specific type of disorder
 - Evaluate the child for related conditions
 - Determine if referrals are needed
 - Identify the cause of the CP



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How Do We Identify Cerebral Palsy (CP)?

- **Steps to early diagnosis**
 - CP generally is diagnosed during the first or second year after birth.
 - If a child's symptoms are mild, it is sometimes difficult to make a diagnosis until the child is a few years older.
 - The link to the NIH information page is in your Take Home Sheet



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Who Should Be Involved In Care?

Who Should Be Involved In Care?

- The caregivers and the child are the focus
- The caregivers, and sometimes the patient (age dependent), should be considered as a member of the team
- Physician
 - Team leader is usually the child's PCP



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Who Should Be Involved In Care?

- Physician: Medical Home
 - The initial assessment
 - Ongoing modification of the diagnosis
 - Incorporation of new information and referral reports
 - Coordination of Care



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Who Should Be Involved In Care?

- Orthopedic Physician
 - Focuses on preventing contractures, hip dislocations, and spinal curvatures
 - Assists in making the diagnosis



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Who Should Be Involved In Care?

- Other physician specialists
 - Depends upon the extended evaluations and necessary treatments
 - Neurology
 - Physiatry
 - Ophthalmology
 - Gastroenterology
 - Urology
 - Psychiatry



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Who Should Be Involved In Care?

- Physical therapist
 - Develops and implements care plan
 - Addresses restrictions, weakness, and abnormal movement
- Occupational therapist
 - Implements care plans focused on activities of daily living
- Speech and language pathologist
 - Implements care plans to optimize communication



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Who Should Be Involved In Care?

- Social worker
 - Assists the patient's family in connecting with the community and assistance programs
- Psychologist
 - Assists the patient and patient's family to cope with the stress
- Educator (e.g., school or ECI)
 - Cognitive or learning disabilities



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Who Should Be Involved In Care?



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Who Should Be Involved In Care?

- So.....Where do we fit in?



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Who Should Be Involved In Care?

- The unfortunate truth is that
 - Not all medical homes function optimally
 - Not all caregivers are compliant or available
 - Not all children have easy access to care
 - Distance to doctor's office
 - Parental time constraints
 - Other obstacles; e.g., COVID-19
 - Limited subspecialist availability; e.g., GAPS
 - Not all specialized services are local to the patient
 - e.g., Proton Beam Therapy



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Who Should Be Involved In Care?

What physician has the time to identify all the problems and put together all the answers?



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Who Should Be Involved In Care?

None of them
have the time or
the resources to
do it alone.



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Who Should Be Involved In Care?

THIS IS WHERE WE FIT IN!



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Who Should Be Involved In Care?



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Who Should Be Involved In Care?

THIS IS WHERE WE FIT IN!

United Healthcare: the unidentified member of the team.



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Who Should Be Involved In Care?
THIS IS WHERE WE FIT IN!

We work with:

- patients
- caregivers
- physicians
- therapists
- social workers
- psychologists
- educators
- hospitals



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Who Should Be Involved In Care?
THIS IS WHERE WE FIT IN!

GOAL:

optimize the patient's
outcome.



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IDEA Law, Section 405, Alberto N.

- **Rehabilitation Act of 1973**

- protection for people with disabilities
- It set precedents for subsequent legislation

- **Section 504**

- Qualifies an individual with a disability
- Shall not be discriminated against on the basis of her or his disability
 - be excluded participation in
 - be denied benefits of
 - be subjected to discrimination
- any program or activity receiving federal financial assistance-**schools**
- any program or activity conducted by any Executive agency
- the United States Postal Service.



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IDEA Law, Section 405, Alberto N.

- **Individuals with Disabilities Education Act (IDEA)**

- the original enactment in 1975
- provide children with disabilities with equal opportunity for education
- tailored to their individual needs

- **Six main elements:**

- Individualized Education Program (**IEP**)
- Free and Appropriate Public Education (**FAPE**)
- Least Restrictive Environment (**LRE**)
- Appropriate Evaluation
- Parent and Teacher Participation
- Procedural Safeguards

- **Subsequent Law: Americans with Disabilities Act in 1990.**



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IDEA Law, Section 405, Alberto N.

Alberto N. v. HHSC Texas 1999

- The Alberto N. case alleged violations of the Medicaid Act, the Americans with Disabilities Act, and the 14th Amendment
- A class action lawsuit in the U.S. District Court for Medicaid beneficiaries under 21 years old who were denied medically necessary health services
- In December 2015, the 16-year-long case came to end.
- The Alberto N. lawsuit resulted in the following changes to Texas Medicaid:
 - Established a definition of medical necessity for Private Duty Nursing (PDN), Personal Care Services (PCS), and Durable Medical Equipment and Supplies (DME)
 - This legal action was predicated on the Rehabilitation Act of 1973 (Sec 504), the Individuals with Disabilities Education Act (IDEA), and Americans with Disabilities Act in 1990.



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IDEA Law, Section 405, Alberto N.

SIGNIFICANCE

- Sec 504 and the IDEA Law are significant terms that are used routinely by educators, psychologists, psychiatrists, and social workers when referring to:
 - Support services
 - School
 - Mandated education
 - Assessment
 - Transportation
- The Alberto N. case is the basis for our obligation to document Medical Necessity.



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What Are The Treatments?


What Are The Treatments?

- What specific treatments or interventions are available?
 - Medications
 - Surgery
 - DME and Orthosis
 - Nutritional Support
 - Treatment of Associated and Secondary Conditions
 - Preventive and Transition Care as the patient matures




What Are The Treatments?

- Medications
 - Botulinum Toxin (botulinum toxin type A)
 - a protein that blocks the release of acetylcholine (neurotransmitter from nerve to muscle)
 - relaxes muscles
 - May be used to reduce drooling
 - ultrasound-guided intra-salivary gland injections
 - Serial Casting to prevent distortions
 - Botulinum treatment has longer lasting effects

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What Are The Treatments?

- Medications
 - Baclofen (Lioresal)
 - Intrathecal (into the spinal canal) baclofen for spastic and dystonic cerebral palsy
 - Used to relax muscles
 - Improves motor performance, reduces pain and spasms, improves sleep
- Complications of therapy
 - Somnolence
 - Hypotonia
 - Headache
 - Nausea
 - Vomiting
 - Infections
 - cerebrospinal fluid leaks
 - seizure activity.

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What Are The Treatments?

- Surgery
 - Selective dorsal rhizotomy
 - Selectively cut nerve roots where they come out of the spinal column
 - Lumbar 1 to Sacral 2 (the low back)
 - Control spasticity
 - Post-op problems can occur
 - proprioceptive loss, bladder or bowel dysfunction, prolonged marked hypotonia, persistent back pain, or spinal deformities

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What Are The Treatments?

<ul style="list-style-type: none">• Surgery<ul style="list-style-type: none">• Selective dorsal rhizotomy<ul style="list-style-type: none">- Selectively cut nerve roots where they come out of the spinal column- Lumbar 1 to Sacral 2 (the low back)- Control spasticity	<ul style="list-style-type: none">• Post-op problems can occur<ul style="list-style-type: none">- proprioceptive loss- bladder or bowel dysfunction- prolonged marked hypotonia,- persistent back pain- spinal deformities
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What Are The Treatments?

- **Surgery**
 - Hip dislocations are a secondary problem from spasticity
 - bracing
 - soft-tissue releases (muscle dissections and muscle/tendon lengthening)
 - major reconstructive femoral and/or pelvic osteotomies (bone surgery)
 - **Scoliosis**
 - Spinal Fusion
 - Spinal tethering



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What Are The Treatments?

- **DME and Orthosis**
 - **Mobility Aids**
 - Wheelchairs
 - Walkers
 - Standers
 - **Orthotics (Braces)**
 - Used to reduce/prevent deformities
 - Can stabilize limbs to improve function
 - Non-surgical treatment of scoliosis
- **Other Devices**
 - Cerebral stimulation to cerebellar cortex by an implantable, controlled-current pulse generator
 - Control spasticity and seizures



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What Are The Treatments?

- DME
- Mobility Aids
 - Wheelchairs
 - Walkers
 - Stenders



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What Are The Treatments?

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What Are The Treatments?

- Other Devices
 - Stimulation to cerebellar cortex by an implantable, controlled-current pulse generator
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What Are The Treatments?

- Nutritional Support
 - Individualized
- Treatment of Associated and Secondary Conditions
 - Appropriate referrals; e.g., Ophthalmology for vision problems/partial blindness
- Preventive and Transition Care as the patient matures
 - Individualized
 - Depends upon the stage in life



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Planning

Many of the CP patients have normal intelligence and can play and interact with peers.

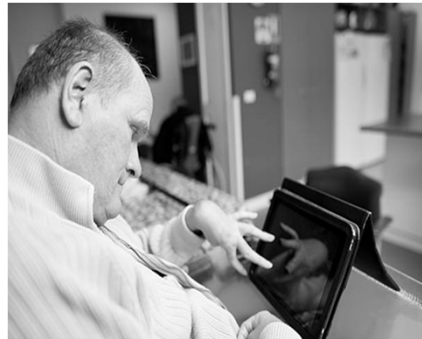


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Planning

- Many have normal intelligence and can work
 - Education planning
 - Retirement planning
 - Transition to independent living



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CP and COVID-19

CP and COVID-19

- **CDC Identifies Children at High Risk for COVID-19**

- **Key Takeaways**

- New data from the CDC details the "medical complexities" that may put kids at an increased risk for severe COVID-19.
- Children without underlying conditions will likely develop only mild symptoms if they are infected.
- Some children with COVID-19 develop multisystem inflammatory syndrome in children (MIS-C), but experts say this is both rare and treatable.



CP and COVID-19

- CDC Identifies Children at High Risk for COVID-19
- “Children who are medically complex, who have serious genetic, neurologic, metabolic disorders, and with congenital (since birth) heart disease might be at increased risk for severe illness from COVID-19”
- This notification
 - In your TAKE HOME SHEET
 - Has since been updated; check the CDC website.



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Conclusion

Conclusion

- CP is an impairment of the brain that usually presents with spasticity
- CP is non-progressive
- Early diagnosis and intervention are very important
- Many patients have normal intelligence and lead productive lives
- Associated problems and secondary problems must be addressed to optimize the patient's independence and well being
- A team approach to the diagnosis and care of patients with CP improves outcomes
- UHC can be of great assistance to the team



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Cerebral Palsy (CP) QUESTIONS?



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