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Care for children and youth with cerebral palsy (GMFCS levels III to V)

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Introduction:

Hi everyone, my name is Juliette Eshleman and I am a medical student at the University of Calgary. This PedsCases podcast on care for children and youth with cerebral palsy (abbreviated as “CP”) was developed with the help of Dr. Scott McLeod, a Clinical Associate Professor at the Cumming School of Medicine in the department of pediatrics, and a Child Health & Wellness Researcher for the Alberta Children’s Hospital Research Institute. This podcast is designed to provide you with an overview of care for children and youth with cerebral palsy, with a specific focus on those who are within the Gross Motor Function Classification System (GMFCS) levels III to V. We will be addressing the following learning objectives in our podcast:

1. Define Cerebral Palsy and the Gross Motor Function Classification System (GMFCS).
2. Discuss the multidisciplinary approach to caring for CP patients.
3. List and describe the “F-words” principles to guide CP management.
4. Identify conditions associated with CP.

Defining CP and the GFMCS:

Let’s start off with a clinical case. You are a third-year medical student working in a neuromotor clinic, and you are asked to see Aaron, a 3-year-old boy who has bilateral spastic cerebral palsy classified as level IV according to Gross Motor Function Classification System (or GMFCS). He is accompanied by his mother for his routine health surveillance appointment, as your preceptor has been following Aaron and his family for several years. Upon further questioning, you learn that Aarons mother is concerned about how he moves by creeping on his stomach, and can take a few steps only when assisted by an adult.

This case lends itself to a discussion regarding the care of this young boy with cerebral palsy, but first we must orient ourselves by defining CP. CP is an umbrella term that includes many more specific conditions, like perinatal stroke for example, all of which have an impact on the movement and posture of a child. These conditions are typically thought of as non-progressive, although the non-progressive nature of them refers to the brain MRI findings, after all, children change and develop with growth all the time. Children with CP should not be regressing in their developmental skills. The differences in movement and posture can be directly correlated with imaging changes, or alternatively even genetic changes that have impact to the central nervous system.

Cerebral palsy is the result of early insult to the developing brain, before 2 years of age, and can present with a variety of symptoms and in a wide range of functional impacts. The extent of the functional impact CP has on an individual depends on the nature and degree of damage. For more information regarding risk factors, clinical presentations, diagnosis and prognosis or CP, you can refer to the PedsCases podcast titled “Cerebral palsy” for an overview of this disorder.

A helpful and validated tool in describing the gross motor function of children and youth with CP is The Gross Motor Function Classification System (GMFCS).

This is a 5-level classification system based on a child's ability to self-initiate movement such as sitting, walking, and wheeled mobility. Need for assistive technology to improve functional abilities is the key to distinguishing between levels. It should be noted that though we are discussing different classification of CP in this podcast, providers should steer away from using terms referential to perceived “severity” of the disorder and instead describe symptoms based on functional impact. Generally, it is felt that severity is a judgement, and as physicians we are here not to judge, but to support the function and goals of children and families.

To illustrate this in the context of today's podcast, a child functioning within in level III can walk with a hand-held mobility device such as a cane or crutches over short distances but would likely use a wheelchair if the distance were longer, or the floor surface were more unstable like outdoor terrain. A child functioning in level IV requires a wheelchair for most distances but can move by themselves using their arms, legs or may use powered mobility, they would also likely be able to stand briefly on a stable surface to assist an adult with transferring them from a car to a wheelchair. A child at level V typically requires a wheelchair and needs someone else to push them. This contrasts with GMFCS levels I-II, as children in these categories range from not requiring any assistive devices for mobility, to relying on handheld mobility devices while maintaining the ability to stand independently. As with GMFCS Levels 1 and 2, the use of mobility aides can depend on other factors such as fatigue and the distance being travelled.

Themultidisciplinary approach to caring for CP patients:

Managing cerebral palsy (CP) involves a team-based approach to address the complex and diverse needs of children and youth, especially those in GMFCS levels III to V. Due to the functional impacts of motor limitations in these groups, a coordinated, multidisciplinary team is essential to optimize their health, function, and quality of life.

At the core of these patients care is a combination of medical, therapeutic, and social support. Key members of the care team typically include:

- **Pediatricians and Neurologists**: Responsible for managing medical issues, monitoring overall health, and treating comorbid conditions such as epilepsy or spasticity. These team members often serve as the “medical home” for children with CP and are crucial to ensuring regular health surveillance through maintaining a comprehensive health and wellness record.
- **Physiotherapists (PTs)**: Focus on improving or maintaining physical function through tailored exercises, stretching, and movement-based therapy. Their goal is to enhance mobility, prevent contractures, and optimize use of assistive devices.
- **Occupational Therapists (OTs)**: Work with children to enhance their ability to perform daily tasks and improve fine motor skills. OTs also evaluate home and school environments to recommend adaptive equipment, such as seating systems, specialized cutlery, or communication tools.
- **Speech and Language Pathologists (SLPs)**: For children with communication or feeding challenges, SLPs provide strategies for improving speech, language, and swallowing. This is particularly important for children with significant oral motor involvement.
- **Orthopedic Surgeons**: In cases where children experience severe contractures or deformities, orthopedic intervention may be required. This can include surgery to lengthen muscles or correct issues such as hip subluxation or scoliosis.
- **Social Workers and Psychologists**: Provide essential support for both the emotional well-being of the child and the family. They can connect families with community resources, support systems, and coping strategies.

Each member of the care team plays a vital role in addressing the holistic needs of the child, from managing medical complications to supporting functional independence and social participation. Given the progressive nature of some complications in CP, ongoing assessment and adjustment of care plans are critical.

The “F-words” in CP Management:

A useful framework that has been integrated into cerebral palsy care is the “F-words,” which stem from the World Health Organization’s International Classification of Functioning, Disability, and Health (ICF). The "F-words" are designed to focus on function, rather than disability, and emphasize participation in everyday life. They include:

1. **Function**: This relates to what children can do, rather than focusing on what they cannot do. For children with CP, the aim is to understand and support the functional goals which are reported by the parent and child. A physician or allied health professional can provide input to help tailor the goals based upon functional abilities and next steps.
2. **Family**: The family is central to a child's care. Supporting the family unit—through resources, education, and coping strategies—is critical for the child's well-being. Non-profit organizations often play a key role in this support, offering adaptive recreation activities, adapted bicycles, and other inclusive programs. These opportunities provide families with fun, meaningful experiences while fostering the child's development and strengthening family bonds.
3. **Fitness**: Physical activity is crucial to maintaining health and mobility, regardless of the child's GMFCS level. Encouraging regular physical activity supports muscle strength, cardiovascular health, and overall well-being. Collaboration with physical therapists and schools is essential to create inclusive opportunities and tailored interventions that ensure every child can participate in physical activities suited to their abilities.
4. **Fun**: Children should have access to leisure and recreational activities that bring them joy and foster social connections. Adaptive sports and activities, such as sled hockey, para skiing, or inclusive playgrounds, can provide meaningful opportunities for children to have fun while promoting social engagement, physical activity, and self-confidence.
5. **Friends**: Social interactions are key for a child's development and quality of life. Promoting relationships with peers is essential, whether in school or social settings. Collaboration between the medical home and schools can help identify and address any challenges a child may face in forming and maintaining friendships, ensuring they have the support needed to build meaningful social connections.
6. **Future**: Planning for the future is essential, including discussions about schooling, transition to adulthood, and future health care needs.

The "F-words" framework encourages a positive, holistic approach to care, focusing on strengths and abilities rather than limitations.

Conditions Associated with Cerebral Palsy:

Children and youth with cerebral palsy, particularly those classified as GMFCS levels III to V, often face a range of associated conditions beyond motor impairment. These comorbidities can significantly impact their quality of life and require careful monitoring and management by their care team. The most common associated conditions include:

1. **Spasticity and Movement Disorders**: Spasticity is the most common type of movement disorder associated with CP, occurring in 70-80% of cases. It is recognized now that often spasticity can occur at the same time as other movement disorders such as dystonia, resulting in a mixed movement disorder profile. Spasticity refers to a velocity dependent increase in muscle tone, leading to stiffness and difficulty with movement. Other movement disorders include dystonia (involuntary muscle contractions) and ataxia (lack of coordination). These conditions are often managed through a combination of physiotherapy, oral medications such as baclofen, focal medications such as botulinum toxin to address pain or caregiving issues in specific muscles groups, and in more complex cases, surgical interventions (e.g., selective dorsal rhizotomy, intrathecal baclofen, or deep brain stimulation). Further helpful information about management of spasticity and dystonia is available within the care pathways of the American Academy of CP and Developmental Medicine.
2. **Seizures and Epilepsy**: Around 30% of children with CP will develop epilepsy. Seizures can range from mild to severe and are often managed by a pediatric neurologist. Anti-epileptic medications are often required, and it is important to carefully monitor seizure control as part of the child's overall health plan.
3. **Gastrointestinal and Nutritional Issues**: Children with CP often experience challenges with feeding and digestion. Dysphagia (difficulty swallowing) is common, especially in those with more significant motor impairments, leading to a risk of aspiration and respiratory infections. Gastroesophageal reflux disease (GERD) is another common issue. In some cases, children may require gastrostomy tube (G-tube) placement for feeding to ensure they receive adequate nutrition. Regular monitoring of growth, weight, and nutritional intake is essential for this reason. Maintaining strong bones is also critical for children with CP, especially those with limited mobility. Adequate calcium and vitamin D intake, alongside weight-bearing activities where possible, can help promote bone health and reduce the risk of osteoporosis.
4. **Respiratory Issues**: Respiratory problems are often seen in children with CP due to factors such as poor airway clearance, aspiration from feeding difficulties, and recurrent respiratory infections. Children with more severe motor impairments (GMFCS levels IV and V) are particularly at risk. Pulmonary care may involve chest physiotherapy, respiratory support, or even surgical interventions to address chronic issues.
5. **Musculoskeletal Complications**: As children grow, they can develop musculoskeletal complications such as scoliosis (curvature of the spine), hip subluxation (misalignment of the hip joint), and contractures (permanent shortening of muscles or tendons). These conditions can affect mobility, comfort, and overall function. Early detection and intervention, often through orthopedic surgery or bracing, are key to preventing further complications. Children with higher GMFCS

levels are at increased risk of hip subluxation due to limited mobility. Routine screening using pelvic X-rays, ideally every 6 to 12 months, is vital to detect early changes in hip alignment. Guidelines are available for the monitoring of hip surveillance on the American Academy of Cerebral Palsy care pathways website.

6. **Cognitive and Communication Challenges**: While many children with CP have typical cognitive development, around half may experience intellectual disabilities or other challenges with learning such as attention differences, or specific learning disorders. In addition, communication difficulties are common, particularly in children with motor involvement affecting their speech muscles. Speech and language therapy, along with the use of augmentative and alternative communication (AAC) devices, can help these children express themselves.
7. **Bladder and Bowel Dysfunction**: Many children with CP experience bladder and bowel control issues, including incontinence and constipation. Management often involves a combination of dietary changes, oral laxatives, or changes in fluid intake.
8. **Pain**: Pain can arise from a variety of sources, including spasticity, musculoskeletal issues, and gastrointestinal discomfort. It is important to regularly assess and address pain in children with CP to improve their quality of life. Pain management may include medications, physiotherapy, and sometimes more invasive procedures.

By being aware of these associated conditions, the care team can provide comprehensive, proactive care to prevent complications and improve the overall health and well-being of the child.

A helpful care checklist is available accompanying this CPS Practice Point on the CPS website.

Conclusion:

Returning to Aaron, the 3-year-old boy with bilateral spastic cerebral palsy classified as GMFCS level IV, who moves by creeping on his stomach and takes a few steps when assisted, his care will involve a multidisciplinary approach.

Physiotherapy will focus on exercises to improve strength and mobility, potentially incorporating a walker for supported walking. **Assistive devices**, such as orthotics to assist with stability of the feet/ankle joints, as well as a 4-wheeled walker for movement practice, and a wheelchair most activities, would help Aaron maintain independence.

Occupational therapy will address daily living tasks, like self-feeding, and provide adaptive equipment. **Speech and language therapy** could be needed if Aaron has speech or feeding difficulties. For managing spasticity, his pediatrician may consider treatments like oral medications or if there are specific muscles impacting function, botulinum toxin injections.

Additionally, it’s crucial to support Aaron’s family by connecting them with community resources and psychosocial support, ensuring Aaron’s needs are met holistically.

By using the **"F-words" approach**, we can focus on Aaron’s abilities, family involvement, and future goals, optimizing his care and quality of life.

That brings us to the end of today’s discussion on care for children and youth with cerebral palsy, particularly those at GMFCS levels III to V. Let’s recap what we covered:
First, we defined cerebral palsy and explored the Gross Motor Function Classification System to better understand its impact on mobility. We then discussed the importance of a multidisciplinary team in addressing the diverse needs of children with CP. Next, we highlighted the 'F-words' framework, which focuses on function, family, fitness, fun, friends, and future to guide holistic management. Finally, we reviewed the associated conditions common in CP and emphasized proactive care to improve quality of life.
Thank you for listening to this PedsCases podcast.

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