

The GREATEST SHOW on Earth

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LADIES AND GENTLEMEN, BOYS AND GIRLS, children of all ages, please take your seats and prepare to be amazed, mystified and entertained! Jugglers keep an array of objects up in the air, effortlessly catching and throwing whatever comes into the mix. High wire artists balance on the edge of potential peril as they traverse a large empty space. Simultaneous events occur everywhere until the audience is drawn to the grand finale. Who would have thought a seating clinic and a three-ring circus would have so much in common? How often does the seating clinic team need to juggle and balance a variety of factors? How frequently does a flaming baton get thrown into the mix of seemingly innocuous items? Many wheelchair grand finales are a result of skirting pitfalls and weighing a multitude of options to find a mobility solution to conclude the show.

THE RINGMASTER

Peter is a 12-year-old young man with spastic diplegia cerebral palsy and a hearing impairment. Diplegic cerebral palsy is characterized as a non-progressive, neuromuscular disorder involving motor or postural abnormalities with greater lower extremity involvement than the upper extremities. In addition, Peter presents with perceptual deficits and difficulties with motor planning. Functionally, Peter's gait is atypical, and he is unable to keep up with his peers. When he was 5 years old, he underwent a selective dorsal rhizotomy. This is a surgical procedure which

involves cutting selected sensory nerve roots in attempts to reduce spasticity in affected muscles. Now that he is older, Peter takes oral baclofen and receives regular Botox injections to his legs. Peter also receives services from both outpatient and school based physical therapy to target both underlying impairments and functional limitations.

THE CENTER RING

The spotlight allows a closer look at Peter. Following a rapid growth spurt, significant limitations are present in the passive range of motion of his hamstrings and adductors. Furthermore, his sitting posture is marked by kyphosis, pelvic obliquity and lateral trunk shortening. These postures and changes in muscle length worsen with the onset of fatigue, when his stability is challenged and during difficult tasks. For Peter, posture is more than just measurements and observations. It impacts the quality of function and his mobility options.

Peter walks with bilateral knee-ankle-foot orthoses and quad canes. However, due to the high-energy cost and his slow cadence, ambulation is not currently a functional mode of mobility, but continues to be used therapeutically and for exercise. At home, crawling is efficient, safe and acceptable. Peter uses a manual wheelchair of his own out in his community and at his sled hockey games. He lags behind his friends and often needs assistance from his parents or other adults to keep up and to limit his fatigue. His public school purchased a power wheelchair eight years ago so Peter could be independent in the educational environment. However, when it is not working, he is forced to rely on his manual chair, causing him to be late to class and often requiring the assistance of an aide to get him around the building and carry his books and supplies. His high school plans are unclear, but his family is considering private education. It is time for Peter's own equipment to bridge two of the rings of his personal circus/school and community. When Peter is asked what he wants out of a new wheelchair, his response is simple. He wants to keep up with his friends, get to class on time without an aide, and of course, look cool doing it!



PETER TRIALS A POWER ASSIST WHEELCHAIR.



LEFT: SEATED POSTURE BEFORE FATIGUE
CENTER: PETER!
RIGHT: PETER TRIALS A POWER WHEELCHAIR

THE AUDIENCE

Peter, like many other children, has the benefit-or the curse-of a lot of professionals guiding his medical and therapeutic management. The extensive team consisting of the young adolescent, his parents, school therapists, outpatient therapists, durable medical equipment suppliers and physicians often have conflicting opinions. All members are rarely in the same room to create a comprehensive plan of care. When they are, the theme music to Ringling Brothers Barnum and Bailey is usually playing. The audience at this particular circus is rather boisterous. Strong voices resonate with concerns of postural alignment and stability, pain, efficiency, maintaining physical activity, accessibility, transportation difficulties and funding challenges. A debate arises, centering around the implications of power, power assisted and manual wheelchair frames. In the presence of the team, Peter's eager to please attitude emerges and his conviction to his own goals is the first disappearing act of the hour. Are the pressures of the spotlight too much?

BALANCING ON THE HIGH WIRE

Peter's perceptual and motor planning deficits challenge his knowledge of where his body is in space and his ability to create and use good strategies to complete a motor task. Unlike his peers on his hockey team with spina bifida, Peter's movements do not occur in isolation. In this young man with cerebral palsy, his whole body requires assessment. Watching Peter propel a manual chair, motor activation occurs beyond the muscles of his trunk, arms and shoulders. Peter's atypical movement patterns are accentuated the longer he pushes and marked changes occur at his legs and pelvis. Initially, his legs are extended, but with fatigue, greater hamstring recruitment emerges which flexes his knees and pulls his pelvis into a posterior tilt resulting in an anterior migration on the seating surface. Subsequently, the relationship between his shoulder and the wheel axle is affected, as well as his propulsion mechanics. With power assist wheels, Peter continues to have postural shifts and compensations, but they do not occur as readily. In contrast, when mobilizing in a

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power chair, Peter's legs are quiet and his pelvis remains stationary on the seating surface. Without controlling posture, Peter is at risk for progressive joint contractures, pressure distribution changes, pain and upper extremity repetitive strain injuries. Up on the high wire, balance is the ultimate goal with optimal biomechanics for the present and the future necessary for a successful act.

SEND IN THE CLOWNS!

A circus is never complete without cramming the whole lot of them into the smallest car imaginable. Well, a station wagon is not the smallest car in the world, but it might as well be when Peter's parents think about trying to put a power wheelchair inside. His family's lifestyle has no room for a van complete with a lift or ramp system. Moreover, the need for an accessible vehicle to transport a power wheelchair would prevent Peter from ever traveling with his friends and teammates. Even the power assist chair, which can be transported in a car, has wheel weights of 25 pounds each. The process to disassemble is not manageable by Peter himself and is challenging for caregivers and friends. In comparison, the manual wheelchair has a total weight of less than 20 pounds and can be managed by any clown in the circus. While the clowns themselves may provide comic relief, thinking about transportation is no laughing matter.

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The Greatest Show...

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INTERMISSION

Get your peanuts, popcorn, cotton candy! Who's buying what? The ticket price on an accessible van with ramps to accompany a power chair is high for the family and not covered by insurance. However, the audience fears insurance denial of power assist wheels due to the increased cost over a traditional power chair. The manual chair appears to be the least costly alternative, but only when considering upfront expenses. Over the next five years, Peter is at risk for secondary impairments from poor postural alignment and improper propulsion mechanics. This may result in future expenses such as additional therapies, medications or surgical procedures.

Looking ahead, Peter's mobility will be further challenged as result of increased environmental demands.

THE JUGGLING ACT

Back in the center ring, a juggler has stepped up with fire. The flaming batons whirl in an effort to create a rhythm between the places where Peter spends his time, his overall physical fitness, and his ability to socialize and keep up with his peers. Looking ahead, Peter's mobility will be further challenged as result of increased environmental demands. His middle school is big, but the high school looms even larger. His neighborhood has a number of hills, and his favorite summer pastime is exploring and visiting local shops. Furthermore, during sled hockey tournaments, Peter often has to traverse long distances within the hotels and the ice arenas. When using a manual wheelchair, the level of endurance, strength and speed required for Peter to function successfully is more than he can generate. However, the audience chants loudly in support of a manual chair to substitute for the decline in physical activity created by the deterioration of independent walking. Even Peter chimes in. His friends use manual wheelchairs, and he just wants to fit in with the pack. But how well does he truly fit in if he is too slow to keep up or requires an adult to push him around? Peter lags behind peers in a manual frame moving at a rate of approximately .831 meters/second accompanied by a high, perceived rate of exertion. In the power assist chair, however, Peter reports a very low rate

of perceived exertion and is able to maintain a speed of 1.19 meters/second, which is comparable to preferred walking speed for adults. Finally, the power chair allows for any self-selected speed without any implication on exertion levels. Each of these flaming batons catches the attention of the audience. The juggler, however, has to balance them all to avoid getting burned.

GRAND FINALE

Drum roll please ... Ladies and gentlemen, direct your attention to the ringmaster. Peter shines in the spotlight, a functional adolescent (if that truly exists) leading all the acts of his circus in his Ti-lite ZRA wheelchair. He uses e-motion power assist wheels for school and long-distance mobility and the manual wheels for shorter community distances and outings. The chair fits in his family's station wagon and he can substitute his manual wheels when a friend or caregiver cannot handle the weight of the e-motion wheels. His postural changes at his pelvis and lower extremities from upper extremity propulsion are managed well in a Ride Designs custom cushion. The custom cushion does not add weight to his system and provides stability to manage his tone and lower extremity position. In addition, his shoulder position in relation to his wheel axle is now more static. The increased stability at his pelvis and use of a posterior Corbac support positively affects his trunk and he no longer shortens on the right side. Most importantly to Peter, the chair is socially acceptable among his friends, and he is now able to keep up on his own. He may be late to class every now and then, but it is not because his mobility was compromised. Finally, the audience cheers as the chair, seating and e-motion wheels are all funded through his private insurance and the curtain closes on the greatest show on earth. ➔

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➤ *Citation for Normative Speeds of Adult Ambulation*
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