WHEN SITTING IN YOUR WHEELCHAIR HIIRTS

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Most of us change our position and orientation multiple times per hour, certainly many times in a day. If we are uncomfortable – worse yet in pain - we change position as we seek to stop or ameliorate it. But what if our position is dictated by positioning and mobility equipment, and we can't shift away from or move out of it? What if we are in pain while sitting in it? Such was the situation for Tre.

I first met Tre in 2017, at age 17. His mother brought him to a 24-hour posture care management workshop I was teaching. He presented with highly complex postural deviations, secondary to his diagnosis of glutaric acidemia type 1 (GA1). GA1 is an inherited organic acid disorder in which the body is unable to process certain proteins properly. This condition leads to abnormal buildup of organic acids,

which accumulate and cause brain damage. This was the source of Tre's cerebral palsy (CP); he was dominated by high extensor tone and spasticity, with posture marked by his extreme torticollis. Over time, his body had become flattened and windswept (see Figure 1). When we first met, Tre's mother, Corinna, explained in addition to CP, he had sleep apnea, autonomic dysreflexia, received nutrition through a G-tube and used oxygen at night. He was non-verbal but answered yes/no questions with facial gestures. Tre and his family live in a remote, rural area of Idaho where travel for any specialized services entails at least two hours sitting in a vehicle.



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Fast forward to March 2021, when Tre was referred to me at age 22 for help with his wheelchair seating. Because he lived more than three hours away, our first session was a teletherapy video call. Through the webcam I was able to see Tre's postural presentation, his equipment and his home environment, while interviewing his mother about his history and needs. While Tre is non-verbal, he clearly responded to my comments and questions with smiles and facial expressions through the camera during the visit. During this call I learned Tre had undergone surgical fusion of his spine with instrumentation, as well as resection of his left femoral head (Girdlestone procedure). He had a pressure injury on his right ear lobe caused by pressure and shear against his head support pad that was nearly healed. He also had a dressed wound on his right heel. Tre spent most of his time in bed because he could not tolerate sitting in his wheelchair, which was about three years old. During the teletherapy visit, I was able to identify some potential wheelchair and seating issues and make preliminary suggestions - the most important being use of Tre's dynamic back. I could see a dynamic back was installed on his wheelchair, however it was locked, and Corinna stated she did not know how to use it. We took care of that in short order, hoping to give Tre the ability to move in his chair for some relief, given his extreme spasticity and extensor tone. Their goal was for Tre to tolerate six hours of sitting in his tilt in space manual wheelchair, with appropriate changes in orientation. At the time, he cried in pain and could not tolerate sitting even two hours.

In August 2021, we actually met in person. As a young adult, Tre was very slender with numerous bony prominences putting him at risk for pressure injuries when coupled with his tone and uncontrolled movements. He presented initially in his manual wheelchair with right trunk rotation, pelvic rotation and obliquity, profound shortening of his hamstrings with strong pelvic thrust, and right wind sweeping of his lower extremities. The Girdlestone procedure had left Tre with a 3" upper leg length difference, shorter on his left. The mat evaluation confirmed that minimal flexibility toward correction existed for most asymmetries. Tre had little control of his movement, with high tone and spasticity dominating. His extreme right torticollis and neck hyperextension caused Tre's visual field to be rearward and toward the ceiling. A combination of cushions, neck pillow, and head support pad were used in an effort to protect his skin and give him adequate support. Tre struggled to tolerate sitting in his wheelchair; and his mother described his crying in pain when he had to sit in it for the two hours required during travel to medical appointments from his home. Therefore, he often traveled lying on the back seat. He had traveled more than three hours to his appointment with me and the supplier.

As we examined Tre's wheelchair, some issues I had noted during the teletherapy session months earlier were confirmed. Tre had a custom molded back support, but sat on a gel cushion that was unstable and bottomed out, leaving him sitting with bony

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prominences on the hard surface of his seat cushion base. Moreover, the off the shelf cushion did not adequately support his longer right upper leg and was too long for his shorter left side, combining with his tight hamstrings to pull him out the front of the cushion. Tre's



Tre's 3-year-old wheelchair FIGURE 2 was too narrow for his windswept posture.

four-point belt was secured too far forward to stabilize his pelvis enough for him to use his dynamic back - he just slid forward and under the belt. The head support was adjusted in symmetry at midline, resulting in excessive pressure and shear as Tre's torticollis and neck extension prevented his resting appropriately in the head pad. The narrow wheelchair fit his slim hips but did not allow for his windswept lower extremities, resulting in excessive pressure laterally where his right leg pressed against the foot rest hanger (see Figure 2). Finally, 60-degree footrest hangers with a foot box could not accommodate Tre's maximum 90-degrees of knee extension. He actually presented with one leg tucked behind the foot box for comfort. Small wonder Tre was in pain and unhappy sitting in his wheelchair.

At this visit we determined Tre would benefit from new custom molded back and seat cushions to stabilize his posture and offload his bony prominences, but we had to schedule a later visit for the shape capture. Meanwhile, we did what we could to provide relief by moving the foot box as far back as possible, although Tre clearly required 90-degree footrest hangers to accommodate his limited knee extension. We also moved Tre's head support laterally to more adequately accommodate his torticollis and reduce the pressure on his ear and cheek, instead of forcing him in a direction he could not tolerate. We moved his four-point belt attachments 3" rearward, which stabilized Tre's pelvis and allowed him to activate his dynamic back. When he extended the back moved with him, absorbing the impact force of his movement, he then appeared to relax somewhat, rather than continuing to push into extension.

This was all we could do, until new equipment could be procured. This included a new custom seating system, parts to widen the

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wheelchair frame for accommodation of Tre's windswept lower body, 90-degree footrest hangers and a taller foot box. We elected to complete these modifications first and then re-assess Tre's head support needs before ordering more parts. With the new seating system, wider frame, and 90-degree footrest hangers, Tre's trunk and pelvis orientation greatly improved, his legs rested in a natural and relaxed position with accommodation of his windswept posture and limited knee extension, and the components of his head positioning system were re-configured to improve support for his head. A longer and adjustable curved pad was recommended for more secure head support, with a tone deflector



FIGURE 3 New head support with mandibular weight bearing surface



FIGURE 4

 FIGURE 5

New system with custom molded seat and back and offset head support pad

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to absorb some of the force when Tre has spasms and extends. These parts were justified and ordered, but their arrival was delayed so that fitting took place six months later.

Finally, a full year after we began the journey to help Tre sit pain-free, the last parts were installed and fit to meet his needs. On the final fitting day, Tre's back and seat cushions were found misaligned, secondary to a side impact car accident when he was riding in his wheelchair secured in his accessible van. The seating system itself was re-adjusted for Tre, and his new head support piece was added. His extreme right torticollis and history of right ear skin breakdown left few safe weight bearing surfaces for contact with the head support. In the end, a long and curved right side pad was adjusted to support Tre at his right mandible an unusual application, but one that is working well for him (see Figure 3). The changes made to Tre's wheelchair frame and seating have been successful thus far. Corinna reports he now sits comfortably in his wheelchair for four hours without crying and has not developed skin breakdown. In her words: "When I look at his wheelchair empty, I can't believe a human being can sit in it (see Figure 4). I need to put him in from the side, to get around the head support. But he's happy in it."

And that is what matters - happy and no longer in pain (see Figure 5).

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Tamara Kittelson is an occupational therapist and ATP/ SMS. She directs Posture 24-7 and Eleanore's Project, promoting 24-hour posture care management and appropriate seating and wheeled mobility provision in low resource settings. She is founding co-chair of the RESNA 24-7 PCM special interest group, and a member of AOTA, RESNA, CTF and is a Friend of NRRTS.

Kittelson has presented and written on these topics nationally and internationally. Kittelson served children and adults with complex neurodisabilities in Montana from 1983 to 2022. She credits her daughter Eleanore, born with cerebral palsy and profound deafness, as her best teacher.