

JOURNEY TO GET A STANDING WHEELCHAIR

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NRRTS WOULD LIKE TO THANK PERMOBIL FOR SPONSORING THIS ARTICLE.

INTRODUCTION:

When the opportunity arises to provide the optimal mobility device to a client, clinicians and providers share the goal of recommending the device with the best possible functional outcome. Given the funding and health care climate we all must manage daily, there are times when our recommendations get overruled by traditional funding sources. This rehab case study will tell the story of a client who was experiencing bone mass loss, decreased range of motion in his lower extremities, increased spasticity, decreased independence in daily activities, and decreased participation in family and school activities. During the evaluation process for new power mobility equipment, the treatment team decided to put best practice ahead of funding limitations and find a way to provide Landon with the equipment that best matched his goals.

BACKGROUND:

Landon and his family arrived at seating clinic with recommendations from a physician to obtain a new power wheelchair. Landon was born at 30 weeks gestation, spending five weeks in the neonatal intensive care unit (NICU). He was diagnosed with periventricular leukomalacia (PVL) which, according to the National Institutes of Health, often leads to cerebral palsy, as it did with Landon. He presented with motor and coordination and weakness, which are deficits associated with spastic quadriplegia. Landon has many loving attributes: he is very active in school, loves to sing, is the oldest sibling of six brothers and sisters, enjoys going to Disney World, and craves to be independent. At the time of the evaluation, Landon was a 14-year-old vibrant, talkative and engaging young man.

“HE WAS DIAGNOSED WITH PERIVENTRICULAR LEUKOMALACIA (PVL) WHICH, ACCORDING TO THE NATIONAL INSTITUTES OF HEALTH, OFTEN LEADS TO CEREBRAL PALSY, AS IT DID WITH LANDON. HE PRESENTED WITH MOTOR AND COORDINATION AND WEAKNESS, WHICH ARE DEFICITS ASSOCIATED WITH SPASTIC QUADRIPEGLIA.”

A thorough evaluation with multiple team members was completed. Landon’s physician was growing increasingly concerned about his bone mineral density (BMD) and related decreased functional



FIGURE 1 Landon standing with posterior walker.



FIGURE 2 Landon seated in previous power wheelchair.



FIGURE 3 Landon having difficulty reaching when in a low seated position.

mobility. In addition, his family reported that as Landon was growing in height and weight, it was getting harder for him to stand independently or ambulate functionally (see Figure 1) and “even a sneeze would make him fall.” They also noticed that when he was seated in his previous power wheelchair, his posture was not as upright as it had been in the past (see Figure 2). In addition, Landon wished to become an independent young adult. His goal was to one day be able to move away, study at college, and get a job like anyone else.

EVALUATION:

Landon presented with impairments in multiple body functions and structures including:

- Increased spasticity impacting all four limbs as well as his trunk.
- Joint range of motion limitations in bilateral hips and knees.
- Osteopenia at the femur.
- Pain and discomfort when sitting for long durations throughout his spine as well as on his or the sitting surface,
- Decreased respiratory capacity and voice production
- A mat evaluation was completed to address postural changes and concerns.

His primary activity and participation limitations included:

- Non-functional ambulation with a posterior rolling walker.
- Requiring more assistance with transfers from family members into a static standing frame.
- Inability to access items in his kitchen at home.
- Difficulty interacting with peers.
- Taking increased time to complete daily care activities.
- Decreased desire to participate in classroom discussions (see Figure 3).

His family already owned an accessible vehicle for his existing power mobility device (a power wheelchair with power tilt) as well as an accessible home (ramped entrance with wide doorways). Landon was able to drive and manage his current power wheelchair independently; however, he noticed there were areas he could not access, or where he would get stuck. In addition, he was uncomfortable and could not change positions the way he needed to.

The occupational therapist and ATP worked with the manufacturer’s representative to obtain a demonstration

power standing wheelchair for Landon to test. Landon was eager to try it out and then procure this device, and his family, clinician, equipment provider and manufacturer sales representative had no choice but to be along for the ride!

During a trial of the standing wheelchair, the team discussed programming options for the standing sequence, back support solutions, and seat cushion recommendations. At this point, the equipment provider informed Landon and his family about any items that could potentially be denied by insurance, so that they could make an informed decision regarding the team’s recommendations. The mobility base recommended was a Group 4 power wheelchair with the following power seat functions: tilt, recline, elevating and articulating leg rest, seat elevation device, and standing. A denial was anticipated for the power seat elevation device and power stand functions including powered anti-tip bars, which are required both for stability and for driving while standing. The family chose to proceed with submitting all items to private insurance and then seeking alternative solutions if needed once a funding decision had been made. The team believed that a power standing wheelchair was the best possible standard of practice for Landon and all parties were committed to any additional time or work associated with achieving these goals.

DETAILED DOCUMENTATION

The team knew that comprehensive documentation would be critical in order for Landon to obtain a power standing wheelchair. The clinical documentation highlighted the following and research was cited when appropriate:

- Increased independence with MRADLs when client utilized a power standing wheelchair when compared to a power wheelchair without the standing function. MRADLs highlighted included meal preparation, grooming, transferring, chores, medication management and feeding activities (see Figure 4 and Figure 5).



FIGURE 4 Landon trying to get water from the sink when seated.



FIGURE 5 Landon getting water while standing in power wheelchair.



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FIGURE 6

Landon felt like he was unable to interact and be independent in the community with previous power chair.

- Increased safety and independence with transfers. In a power wheelchair without the seat elevation device, he required maximum assistance for a stand pivot transfer. In a power wheelchair with only the power seat elevation device (not power stand), he required moderate assistance for stand pivot transfer. In a power wheelchair with only power stand, he required minimum assistance for a stand pivot transfer.
- Power adjustable seat height required for transfer activities, reaching tasks in a classroom setting when he requires a pressure relief from being in the standing position as well as increased independence with standing, reaching, elevator button access when an environment does not accommodate a power standing position.
- Improved pressure management with power stand when compared to power tilt and power tilt and recline alone.
- Client requires power tilt and power recline for pressure management when power standing is not able to be achieved due to environmental limitations or pressure relief from lower extremities in addition to safety when driving his power wheelchair due to kyphotic posture, balance and stability when negotiating uneven terrain and negotiating ramps.
- Power recline is required for positioning to manage spasticity that results in excessive hip, knee, and trunk extension, which limits his functional use of his lower extremities.
- Power elevating leg rests are required due to lower extremity edema management as well as to achieve

specific safe knee position for anterior tilt as well as standing. In addition, recline cannot be used without power elevating leg rests due to the strain on two-joint musculature of the hamstrings and quadriceps due to decreased hip and knee range of motion.

- Improved spasticity management in the lower extremities with power standing trial that could not be obtained from any other power mobility device.
- More frequent standing bouts throughout the day to address osteopenia. With a power standing wheelchair, client can stand independently. The use of a static standing device required maximum assistance for transfers and moderate assistance to enter and exit a standing position. Landon was dependent for MRADLs in a static standing frame, but with the power standing chair, he was independent brushing his teeth, washing his hands and getting a drink.
- Landon was showing decreased ability to participate in school and social activities due to pain, decreased line of sight, discomfort, lack of voice production, increased need for overhead reaching, and becoming more withdrawn using a power wheelchair with tilt only (see Figure 6).

Medical, clinical and equipment provider documentation was completed and submitted. The first communication from the private insurance company was a denial letter and although anticipated by all from the beginning, was still disheartening. The primary items denied included power seat elevation device, power stand and drive components. On this specific power wheelchair base, the power seat elevation device is required along with other power seat functions to achieve the ability to transition into a standing position, and Landon required the use of the seat elevator independently of standing. For example, certain environmental limitations may require a seat elevator based on the surface height he needed to reach. Let's take a soap dispenser in a public restroom. If he was standing, his reach would actually exceed the height required; however, if he was able to utilize his power seat elevation device and increase his reach by just 4 inches instead of 10 inches, he would be at the perfect height to access the soap dispenser independently.

“ON THIS SPECIFIC POWER WHEELCHAIR BASE, THE POWER SEAT ELEVATION DEVICE IS REQUIRED ALONG WITH OTHER POWER SEAT FUNCTIONS TO ACHIEVE THE ABILITY TO TRANSITION INTO A STANDING POSITION AND LANDON REQUIRED THE USE OF THE SEAT ELEVATOR INDEPENDENTLY OF STANDING.”

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Upon the first round of appeals led by the treating clinician and the equipment provider, the team was able to successfully obtain approval for the power seat elevation device. This was an amazing success for Landon and his team, as it was the first time this device was ever approved by their specific private insurance company.

However, the journey to a standing power wheelchair was not complete. The family appealed the power stand function denial a second time, but to no avail. Despite medical, functional, social and psychological benefits clearly outlined and supported, the power stand function was still denied. At this point, Landon was not ready to give up and neither was his team. They investigated all alternative funding solutions and, with support from a nonprofit foundation, were able to obtain funding for the remaining denied items. In addition, the equipment provider agreed that they would provide service to any noncovered item related to the power stand function.

Landon's journey to stand was an incredibly big undertaking that did not happen overnight. It was almost a one-year-long process, and all team members were in support of the additional time, energy, and cost that was required. However, through perseverance, creativity and support, Landon was able to achieve his goal of standing whenever, wherever, and however he wanted to.

OUTCOMES:

When an opportunity presents itself, Landon seizes it and doesn't look back. With his power standing wheelchair, he has seen a tremendous amount of improvement in his physical health, functional independence, social interaction, family participation, communication, and overall quality of life.

Six months following the provision of his power standing wheelchair, we followed up with Landon to see how he was doing and to evaluate how the power standing wheelchair was impacting his life. He reported the following:

- Reduced cervical and lumbar spine pain.
- Elimination of pain at his sitting surface.
- No further loss of hip and knee range of motion

FIGURE 7 Landon's upright seated posture improving with use of power standing wheelchair and positioning components.



FIGURE 8 Landon successfully accessing kitchen cabinets.



FIGURE 9

Landon looking at himself upright in a mirror for the first time.

**FIGURE 10**

Landon interacting and playing with younger siblings.

- Improved upright seated posture (see Figure 7) with decrease of his reducible posterior pelvic tilt and thoracic kyphosis which, in turn, improved his line of site, respiration and voice production.
 - Increase in bone mineral density as determined by his physician.
- Although no generalized statements can be made from these results, we can see below that after receiving the power standing wheelchair, the standard deviations on his lumbar spine Z-Score improved remarkably. This may indicate preservation of remaining bone mineral density in the future.

CLIENT LUMBAR Z-SCORE MEASUREMENTS

DATE	LUMBAR SPINE Z-SCORE	BONE MINERAL DENSITY
May 2017	-1.6	.528
December 2018	-2.5	.491
February 2019 — 6 months after provision of power standing wheelchair	-1.1	.565

Functionally, the improvement in Landon’s independence exceeded our expectations! He was able to get items out of his kitchen cabinets (see Figure 8), pour a glass of water, write on the white board at school, wash his hands and look at himself in the bathroom mirror for the first time (see Figure 9).

Participation and social activities also improved. His bean bag toss score improved when playing with his siblings (see Figure 10). Landon returned to the choir (see Figure 11) as he noticed an improvement in his singing voice, and shares: “It is kind of cool to be able to stand and sing, because you know that is how you do it, that is the proper way to do it.”

CONCLUSION:

Funding challenges can be a deterrent or barrier to what we want to do for our clients — provide the most appropriate mobility solution. Landon’s case set a precedence with his private insurance in that they paid for a power seat elevation device after appeal; so not only will Landon benefit from this approval, many others will as well.

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“LANDON’S CASE SET A PRECEDENCE WITH HIS PRIVATE INSURANCE IN THAT THEY PAID FOR A POWER SEAT ELEVATION DEVICE AFTER APPEAL; SO NOT ONLY WILL LANDON BENEFIT FROM THIS APPROVAL, MANY OTHERS WILL AS WELL.

In closing, we can continue to show successful interventions for items not traditionally funded by documenting changes from a child and parent’s perspective through a “participatory photovoice” or photo journey (Feldner, Logan & Galloway, 2018). Along with comprehensive documentation, evaluation and teamwork can help to inform practice decisions in the future. It is our hope to continue to follow Landon to obtain objective outcome measures for medical, functional, and quality of life indicators — but also to see the joy on his face for years to come. Take it from Landon “[t]his was very important because it has increased my independence and my self-esteem” (see Figure 12).

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REFERENCES

Full references available upon request



FIGURE 11 Landon in choir practice.

RESOURCES

Alternative Funding Resource List from Permobil: <https://cdn2.hubspot.net/hubfs/1624307/Education%20Resources/AlternateFundingDoc.pdf>

RESNA position on the Application of Wheelchair Standing Devices: https://nrts.org/wp-content/uploads/2019/06/RESNAStandingPositionPaper_Dec2013.pdf

NCART Standing Device Funding Guideline: <https://www.ncart.us/uploads/userfiles/files/ncart-standing-device-funding-guide.pdf>

FIGURE 12 Landon feeling confident and increased self-esteem



Jennith Bernstein is a physical therapist based in Atlanta, Georgia. She has focused her career on seating and wheeled mobility, beginning at the Shepherd Center. Bernstein completed her master’s in physical therapy at North Georgia College and State University and return to complete her transitional DPT at the University of Texas Medical Branch in 2014. Bernstein has served as a volunteer teacher in Guatemala as well as presented at national and international conferences.



Bernstein joined Permobil in 2016 as a regional clinical education manager.