REHAB CASE STUDY



EXPLORING (SOME) IMPACTS OF LIMITED BATTERY CAPACITY IN POWER WHEELCHAIRS

Written by: JEFF PRESTON, PHD

I was an active child growing up in a rural Ontario town where kids invented their own fun. Playing sports, going on hikes, building forts - I was always happiest ripping around outside with friends. Contrary to a medical prognosis of a sedentary life due to a profound congenital physical disability, I was determined to be in perpetual motion. This defiant spirit was fueled by an array of mobility devices that augmented my near non-existent physical strength, with everything changing when I received my first battery-operated scooter. Where previously I relied on others to push my manual wheelchair, suddenly I was given the power to chart my own path forward ... even if I was still (significantly) slower than kids without disabilities. "You might be faster than me, but you'll get tired before my batteries die!" I would bellow when playing tag, determined to overcome my speed limitations with a longitudinal zombie-inspired strategy. It is hard to articulate the impact of transitioning to full-time use of an electric wheelchair (sometimes called powerchairs) but nearly three decades later I can no longer imagine a world without it.

While my powerchair opened a world of possibilities it was, ultimately, an imperfect solution. Aside from the speed deficiencies, breakdowns and limited battery capacity would plague my early years — the devices were simply not capable of keeping up with my childish exuberance. When the batteries would die, I was left reverting back to my manual chair and, once again, reliant on those around me. Frustrated by the near

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constant interruptions, my family reached out to specialists, technicians and manufacturers only to receive the same explanation: despite being made for children, these wheelchairs were expected to be used in institutional settings and were not designed to handle road hockey, muddy forests or salt- and snowcovered playgrounds. Ultimately, my playful spirit was bound by the comparatively narrow imaginations of the wheelchair industry. While the construction and technology of powerchairs has evolved over the decades, along with enhanced durability of adult chairs, I continue to live a life bound by the technical limits of the powerchair, with days sometimes cut short by dwindling battery power.

EXPLORING BATTERY LIFE

Something I learned early on in my time as a powerchair user is there is a certain level of unpredictability in how long a battery charge will last. While most powerchairs can all but guarantee a full day use on a single charge, meaning you can remain in motion so long as you are able to charge the batteries every night, there can be huge differences in functional distance between powerchairs. Part of the variance from chair to chair is derived from the different sizes of batteries — some chairs will use a small single dry cell battery while others will use two large car batteries. But even when comparing chairs that use the same type of battery there can be broad differences. An Invacare Storm I used in my early 20s was able to drive nearly 50km on a single charge whereas my current Permobil F3 has a range of approximately 25km. These batteries are often buried within the chairs, making it difficult to "swap" batteries, and funding programs in Ontario do not generally cover multiple sets. And, like people, batteries grow old and no longer hold the same level of charge, meaning one must monitor their batteries to time replacement — not too soon, before funding programs will cover replacement, but not too late and risk lacking enough power to



Dr. Jeff Preston delivering a keynote at a national conference of Motion in 2018, using the seat elevation feature on his (habitually muddy) Permobil powerchair to reach the lectern.

make it through a day. In my experience, powerchair controllers offer woefully simple battery gauges that rarely offer nuanced accounts of remaining battery function. These gauges often feel more like a simple binary of "everything is fine" or "you are moments from (battery) death." I live by the dichotomy: when fully charged there is enough battery to get through the day but too much usage could bring everything to an abrupt halt. I must then cautiously allocate my precious electricity usage wisely to have enough power for the day.

When everything goes to plan, my life is not interrupted by battery issues. But when things do go wrong, or the battery is not properly managed, my life becomes inextricable from the battery's life. What is typically an invisible, but necessary, force of life becomes the first domino in a chain of failures that leave me both immobile and irritable. To better understand the role batteries play in the life of a powerchair user, I thought it best to share two examples of how things can (and have) gone wrong and the resulting cascade of disabling effects.

EXAMPLE 1: HOLDING A CHARGE

There is nothing more frustrating than waking up in the morning to discover your batteries were not charging during the night. Perhaps with pre-bedtime routines your support worker forgot to plug it in, or the charger was unplugged by a different worker who needed the outlet and no one noticed. Maybe the charger itself has malfunctioned or the power went out. My powerchair can typically survive two days without charging, but it means carefully rationing the battery that remains. I must strategically plan necessary movements and potential times of stasis to recharge throughout the day. When plugged in, my powerchair cannot move and features like automatic tilt and recline are disabled, meaning I must find the perfect position to sit still for as long as possible. To do this, I must reorganize my day on the fly to minimize moving around and find support workers who might be available later in the day should the battery die — an already complex and intersecting schedule system grows ever more cumbersome. It also means determining and eliminating all non-essential movement: while I cannot skip class, as the professor, I can sacrifice going on a walk with my partner after dinner. In a world shaped by neoliberalism, priority has always gone to life sustaining activities, like hygiene and labour, as opposed to life enriching activities, like athletics or socializing.

Should my strategic planning fail and my powerchair dies during the day, the only way to remain mobile is to switch over to a back-up manual wheelchair, as the extreme weight of my powerchair, which weighs over 350 pounds without me in it, is difficult for others to push. Switching to my manual chair comes with other challenges, including becoming fully dependent on others to move and the musculoskeletal pain from not using the highly customized seating and recline package on my powerchair. While switching over to another chair makes the most sense, giving my powerchair time to recuperate, it has generally been an option of last resort for these two key reasons.

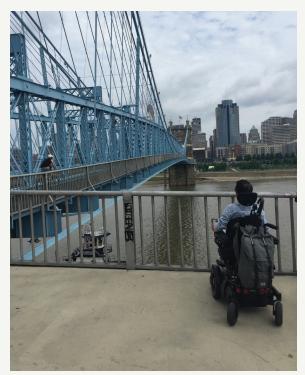
CONTINUED ON PAGE 40

THE PHRASE "CONFINED TO A WHEELCHAIR" HAS ALWAYS SEEMED ANTITHETICAL TO ME AS A WHEELCHAIR-USER. IN MY EXPERIENCE, MY POWERCHAIR DOES NOT "CONFINE" ME BUT, RATHER, PLAYS A CENTRAL ROLE IN MY EMANCIPATION.

BATTERY LIFE ... (CONTINUED FROM PAGE 39)

EXAMPLE 2: MISSED THE BUS

During my undergrad, I was given a unique opportunity to complete a practicum with the communications department of a local rehabilitation facility. Excited to start applying some of my learning in the "real" world, I accepted the position without considering how I would get to my placement —



Dr. Jeff Preston overlooking the water beside Cincinnati's baby blue John A. Roebling Suspension bridge while on vacation.

the facility was on the other side of the city. Because I could not afford an accessible vehicle of my own, I was dependent on the municipal transit system, which offered both specialized and semiaccessible conventional bus services. Unfortunately, neither of these services could reliably get me to work on time and after a first week marred by late arrivals and concerns of getting in trouble, I made the determination to start driving myself to work in my powerchair. While I had enough battery to get me there and back, approximately 60 minutes of driving through the city one way, I quickly discovered this left me with little battery in the evenings to venture far from home. Like days when my powerchair has failed to charge, I was again faced with a difficult decision: prioritize work and professional development over socializing during the week. While I was able to get out of the house on weekends, my social bonds withered that summer. Aside from activities on campus, which were sparse in the summer, most of the restaurants, clubs or theatres were well beyond the range of my remaining battery life, meaning I was spending more and more time at home. It likely goes without saying that this disrupted my work/life balance and made me seriously question how I would manage after graduation.

CONCLUDING THOUGHTS

The academic field of disability studies, a space I call home as an associate professor at King's University College, ostensibly originated several decades ago with the articulation of the social model of disability, a counter-hegemonic perspective that draws into question the dominant medical definition of disability that centers impairment and bodily difference. British scholars like Mike Oliver and Colin Barnes explain that under the medical model, which continues to dominate our understanding of disability, disability is largely seen as an individual problem found within dysfunctional bodies. Under this zeitgeist, terms like "confined to a wheelchair" emerge, with the device becoming the manifestation of a sinister bodily corruption that disables people. On the contrary, social model proponents argue that external factors, such as architecture or discriminatory attitudes, can also be disabling and are perhaps even more important to ameliorate. The social model playfully probes, "is Jeff disabled by his diagnosis or by the stairs leading to the lectern at the front of the classroom?"

Applying the social model, I believe we must increase our complexity of thought when it comes to batteries and adaptive devices. Rather than seeing batteries as an afterthought, we must understand that they can play a vital role in (dis)abling users. This could mean, at the design and manufacturing level, striving to gather better data on how long batteries typically last and developing more detailed information, such as accurate charge readings or how many kilometres of charge remain, on controller displays. We should invest in 'fast-charging' battery technology and facilitate guick swapping of batteries to provide for better redundancy, effectively doubling the range of a powerchair. Finally, none of these changes will matter if we don't also reimagine policies that currently stifle innovation in powerchair technology, such as common government or insurance company policy that opt for cheaper, albeit heavier, dry cell batteries over lithium batteries that could charge faster and last longer.

The phrase "confined to a wheelchair" has always seemed antithetical to me as a wheelchair user. In my experience, my powerchair does not "confine" me but, rather, plays a central role in my emancipation. Without my powerchair I am static, dependent, immobile. In my powerchair I am dynamic, selfdetermining, in motion. For me, my powerchair is central to my life, a kind of Swiss army knife with multiple functions that go way beyond promotional materials or therapist definitions. Most obviously, it is a tool of mobility and access for me and others, be it friends who would ride on the back when I was young or dogs that are led by it on walks. It is sports equipment, for playing hockey or going on hikes and a social enabler, when going to the movies or hitting the dance floor. It augments my limited strength, used to push doors open, move furniture around the house or assist in pulling off heavy jackets. It is a part of me, both literally and figuratively, in that people recognize it as mine but also how its movements reflect me, from speeding around campus to my slow deliberate pacing back and forth while delivering a lecture. Like the clothing I wear, my powerchair is an embodiment machine that manifests "me." We bring each other to life: without it, I could not live; without me, it would be inanimate.

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