The saying goes that sometimes the best lessons in life are learned the hard way. These are the lessons you don’t forget and hope not to repeat. Unfortunately, in the field of Complex Rehab Technology (CRT), these “lessons” may also come at a high cost, literally or figuratively, for those team members who participate in the wheelchair provision process. This may include the clinician, the technology supplier, and of most concern, the wheelchair user.

I was a firsthand party to one of these lessons recently when working as part of an assessment team to help a client determine his best options for a replacement power wheelchair. As a team, we made the risky decision to switch this client from a rear-wheel drive (see Figure 1) to a front-wheel drive (see Figure 2) power wheelchair. Alex (pseudonym) came to our clinic for an evaluation because his existing power wheelchair was very old and requiring expensive repairs repeatedly. In addition, his mouse emulation software was unreliable and failing. In recent years, Alex had come to rely heavily on accessing his smartphone through his joystick. This technology enabled him to communicate with his employer and his caregivers and to browse the internet for shopping and other home management tasks. He hoped to improve his ability to consistently access his smartphone in a replacement power wheelchair.

Alex has a diagnosis of cerebral palsy and has severe muscle spasticity and extensor tone that significantly limits his ability to use his arms and legs. As a result, he operates the power wheelchair with a joystick located at his chin using head movements. Alex used multiple iterations of the same model of power wheelchair for more than 20 years prior to this evaluation. Over the course of those years, he identified very specific seating supports that give him the most control over his head movements, such as custom armrests with upper arm and forearm straps placed at a specific height. Alex also learned how to use the electronic settings on his chair at a highly detailed level.

Given the complexity of his needs and his detailed knowledge of the power wheelchair system, we were hesitant to consider a different wheel configuration. Unfortunately, replacing Alex’s chair with the same, but most updated model of power wheelchair would not resolve his problems with mouse emulation. Given
the importance of this goal, we decided to consider other power wheelchair options that also had reliable mouse emulation technology. We considered other models of rear-wheel drive power wheelchairs first, to minimize changes in how the chair would turn, function and travel at high speeds, as well as handle on rough terrain. Unfortunately, we had to rule out all other rear-wheel base options for various reasons, such as an armrest style that would not meet his unique needs or limitations related to power tilt and recline capability.

Next, we considered mid-wheel drive options (see Figure 3) because we believed changing from a rear-wheel base to a mid-wheel base would be less drastic compared to shifting to a front-wheel base. While the rear-wheel and mid-wheel bases certainly perform differently, the differences in turning radius and drive characteristics, particularly at high speeds, would require a smaller learning curve than would a shift to a front-wheel drive. But once again, we had to rule out the mid-wheel options because this wheel base would not adequately navigate the rough terrain Alex regularly encounters.

As a result, we decided to consider a front-wheel drive base, knowing this would require a larger learning curve for Alex, who had used the rear-wheel model successfully for so many years. Our experiences taught us that Alex learns quickly and is very resourceful and adaptive. Alex also expressed a high degree of interest in trying a different wheel base configuration.

Although not easy, we arranged for the wheelchair manufacturer of a front-wheel drive power wheelchair to set up a demo chair for Alex to use on a trial basis. We did our best to simulate his seating, mount a chin joystick in the proper location and give him the armrest support he requires. It was not perfect but approximated his needs for the purpose of a limited equipment trial. Alex took the chair for an extended period and drove it inside the clinic building and also outside in the immediate community. He completed the trial feeling confident that the front-wheel drive base would work well for him. Although we were nervous about recommending a different wheel configuration, we were reassured by Alex's confidence. We proceeded with making specifications for a replacement power wheelchair with a front-wheel drive configuration. The new chair was approved by the insurance provider three months later.

Once the chair was approved and ordered, Alex returned to our clinic for the fit and delivery. This session was very complex and time-consuming, taking nearly six hours to complete. At this session, multiple people were needed to help install the seating system, set-up and program the chin joystick and power seat functions, integrate Alex's smartphone with the Bluetooth mouse emulator, and provide training and support to Alex in the operation of the new power wheelchair. Alex left our clinic very happy and excited with his new device. Unfortunately, his enthusiasm for the new chair was short-lived.

In less than 48 hours, we received a call from Alex that confirmed our worst fears. Alex contacted me and the technology supplier to let us know he could not accept the new power wheelchair. He had tried to use the system in his home and community but identified several problems that he felt were unacceptable. Operating the power wheelchair with this configuration was too difficult in his home given the differences in turning characteristics and the location of the casters. He also complained that he felt very unsafe and unstable when operating the chair at high speeds because he was not accustomed to making course corrections with this wheel base configuration. The chair performed differently, and he realized that these differences were much more significant than he originally recognized. He knew without a doubt that the power wheelchair would not work for him.

Alex was willing to start the evaluation process over again, even though it would be several months before he could receive a replacement device. He wanted to replace his power wheelchair with the same model as his current chair, knowing that he would have to forfeit his goals for mouse emulation. As a result, we started the assessment process over again. It took nearly 18 months after the original evaluation session for Alex to receive his replacement power wheelchair. Unfortunately, he had to endure multiple equipment problems while waiting for a new system. In addition, we spent countless hours as a team engaged in evaluations, equipment trials,
and fittings that could have been avoided. The technology supplier also incurred the costs associated with taking a power wheelchair back after it is refused. For all parties involved, and especially for Alex, the costs associated with this mistake were significant.

In hindsight, making the shift from a rear-wheel base to a front-wheel base was much more risky than we originally suspected. Based on this experience, I believe we should have made arrangements for a demo chair that Alex could have used beyond just a few hours. He needed a trial device that he could use in all of his home and community environments over an extended period. Using this device in his natural environments was especially important so that Alex could recognize the idiosyncrasies that a change in wheel base configuration could have on his daily functioning. At the time, the thought of setting up a demo chair that would meet his very complex needs for an extended period seemed overwhelming and too difficult.

In the end, we learned that thoroughly exploring the ramifications of a change in wheel base configuration, especially one of this magnitude, is a crucial step no matter how time consuming or challenging it might seem to set up a trial. Ultimately, we were able to get a power wheelchair that meets Alex’s mobility needs, but it was disappointing that he could not access his smartphone as he had hoped. Fortunately, smartphone technologies have improved in recent years, and Alex is now able to operate his phone using voice commands for most of his important tasks. Nevertheless, this situation highlights the need for manufacturers to offer reliable mouse emulation technologies on all wheel base styles.

While this was a lesson we learned the hard way, our experience can hopefully help others take pause before recommending a dramatic change in the configuration of a user’s wheel base. It is certain that every person is unique, and making this type of change will be much easier for some wheelchair users than others, but the potential negative consequences are not to be ignored. Factors that likely made this shift particularly difficult for Alex include his extensive use of a rear-wheel drive system over many years, and his use of an alternative drive control method.

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Using neck movements to operate the chair is a challenging task as the user can only make small and unvaried motor movements with these muscles (compared to a more traditional method of driving, such as using the hand). For Alex, learning a new way to turn the chair and correct his course was challenging under these circumstances. Regardless of the complexity of the user, however, I will always strive for an extended trial in the natural environment for all future clients who are considering a significant change in wheel base configuration.

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