

# RIGHT STANDER. RIGHT TIME.

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The right equipment at the right time can make the difference between using standing equipment and it becoming a nice coat rack. Usually, these articles only include one client, but I'm including two, each with different issues yet a similar theme of providing the right equipment at the right time so that the family will use it.

The first case focuses on the importance of considering many product options with the family to assure best outcomes. The second case shows the limitations of standers in active teens and the potential results of stopping regular standing.

## LINCOLN

Lincoln is a 4-year-old with the diagnosis of myotubular myopathy. He is a bright and engaging young man. He has a tracheotomy and uses a ventilator full time.

Lincoln was referred to me at 12 months old for an evaluation for a wheelchair and a stander. As he has no cognitive impairments but has very little active movement, he was evaluated for, and eventually received, a Permobil Koala power wheelchair that he operates with an Adaptive Switch Labs (ASL) switch tray (for a fun story, ask me sometime about the appeal hearing for his wheelchair – that was super fun) (See Figure 1).

Based on Lincoln's decreased strength, very poor trunk and head control, and his use of a ventilator, an R82 Caribou supine stander was prescribed for him (See Figure 2). This was also chosen based on sizing and appearance. It was one of the few supine standers that was small enough for him. I'm happy to report that there are now many more options.

**THE FIRST CASE FOCUSES ON THE IMPORTANCE OF CONSIDERING MANY PRODUCT OPTIONS WITH THE FAMILY TO ASSURE BEST OUTCOMES. THE SECOND CASE SHOWS THE LIMITATIONS OF STANDERS IN ACTIVE TEENS AND THE POTENTIAL RESULTS OF STOPPING REGULAR STANDING.**

At the time, Lincoln was 31" tall and only weighed 22 lbs. After a lot of work by the supplier to get the tray below shoulder height where he could use it, this stander was initially very easy for the family to use. They used it regularly and Lincoln enjoyed being upright.

Three years later, Lincoln and his family came back to me because he could no longer use the stander (See Figure 3). He was now 42" tall and



Lincoln Power Wheelchair



Lincoln first stander new



Lincoln First Stander Old



Lincoln second Stander



Daniel medical stroller



Daniel First Stander

he weighed 33 lbs. He was too tall for this stander and it had become difficult for his family to operate.

To be honest, I do not use many supine standers in my clinic. Most of the young children I work with have better or improving head control so I usually choose a multipositional or occasionally a sit-to-stand stander. I do not choose sit to stand as much for very young children, as these tend to be more expensive and most payors in Florida do not like the price point.

In discussions with the family and supplier, it became clear that a different style of supine stander was better for Lincoln. The current stander could have been grown into a larger size but the family felt it was difficult to use and did not feel as safe positioning him into it now that he was taller and still had very low function.

The supplier suggested a more basic supine stander by Rifton with less moving parts and less attachments to position and support Lincoln (See Figure 4). After a home trial with the recommended stander, his family was

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very pleased with the new device so this was requested and delivered to them.

Lincoln has had his stander for just over a year. He's continuing to grow so he's now 43" tall and he weighs 45 lbs. His mother reports they are still able to use the stander without difficulty. His passive motion in his legs remains good.

In another few years, it will be time to evaluate Lincoln again for a new stander. As we did with each evaluation, we will start from scratch and determine he and his family's needs based on his current function, size, and the equipment options available.

### DANIEL

Daniel is a 15-year-old who is a very active young man. He enjoys skiing, horseback riding, and he is the manager of his high school football team. He has a lot of friends and is a very active young man.

I first met Daniel in 2003 when he was 8 months old (See Figure 5). He was born with a gap in his spinal cord from C5 to T1 making him a complete quadriplegic at the C5 level. Fortunately for Daniel, his parents accepted his disability and worked to maximize his function from the very beginning.

His first visit to my office was for a medical stroller. His parents were transporting him in a standard stroller. Daniel had poor trunk control, could not sit independently and did not have good use of his upper extremities. His passive

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motion was great despite having spasticity in his lower extremities. He had already experienced a few urinary tract infections, as he was being catheterized.

During that visit, we recommended the medical stroller and his first sit-to-stand stander, an EasyStand Magician EI (this stander no longer exists but is similar to the current Bantam Extra Small) (See Figure 6). We knew that Daniel was never going to stand independently, and we really wanted to maximize his function and lessen the negative effects of sitting from a young age. Our goals back then were to help deepen his acetabulum depth, prevent lower extremity contractures, lessen his spasticity, and lessen his risk of urinary tract infections.

Daniel received his stroller and his stander a couple of months later. His family quickly got into a routine of using the stander daily for at least an hour. He has getting therapy regularly and his function in his arms improved.

Two years after getting the medical stroller, he tried his first power wheelchair. This was very successful as he was very motivated to move himself and quickly learned to operate the wheelchair. After working with his supplier and insurance company, Daniel got his first power wheelchair (See Figure 7). Once he received this, sitting still became difficult for him, as it is with any child.

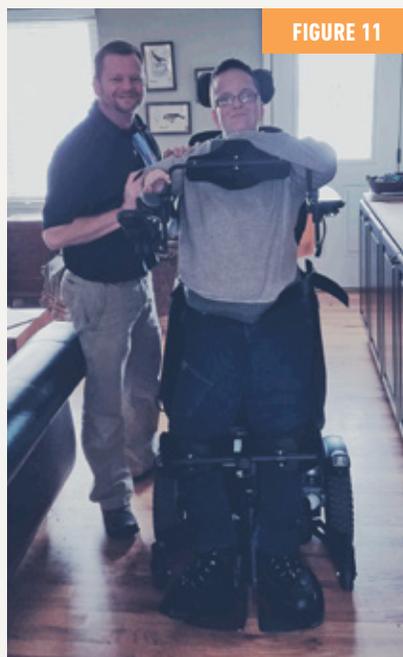
Daniel used the original sit-to-stand stander for two years before growing out of the seating system. Fortunately, we were able to grow the system into a larger seat and back so he could continue to stand (EasyStand Magician conversion ... again, not made



Daniel First Stander



Daniel Activities



Daniel Permobil VS with TD Schenck



Daniel Activities



Daniel Glider

**THIS WAS VERY SUCCESSFUL AS HE WAS VERY MOTIVATED TO MOVE HIMSELF AND QUICKLY LEARNED TO OPERATE THE WHEELCHAIR. AFTER WORKING WITH HIS SUPPLIER AND INSURANCE COMPANY, DANIEL GOT HIS FIRST POWER WHEELCHAIR.**

## I'M NOT SAYING THAT STANDING FOR DANIEL SOLVED ALL THE PROBLEMS IN THE WORLD. IT COULD BE COINCIDENCE THAT HE LOST ALL THE MOTION AROUND THE SAME TIME HE STOPPED STANDING.

anymore). He did not always stand every day for as long as he did originally, but his family still prioritized standing.

Unfortunately for me, Daniel's father changed jobs and the family moved to Denver, Colorado. However, I was lucky that his mom has kept in touch and allowed me to assist them in equipment decisions over the years. Through the magic of email and social media, I've also gotten to watch him grow up and excel.

Over the next few years Daniel got a larger power wheelchair and, thanks to a much better insurance industry than here in Florida, he also got a manual wheelchair. With his function, he was able to self-propel the manual chair some of the time and even used it to play some sports. He even participated in some camps where he got to play sports (See Figures 8 and 9).

Simply standing in a static stander got boring for him considering his energy level and his ability to move himself. So, when he was 7 years old, we decided he could benefit from a glider (See Figure 10). He liked being able to exercise in the stander. We also liked the additional benefits of dynamic standing, which could better assist with maintaining bone density than static standing.

As Daniel got older and busier, taking time to stand became more difficult. Between schoolwork and extracurricular activities, he stopped standing. As a result, he started to lose passive motion in his lower extremities.

Daniel performed a trial with a standing power wheelchair when he was 14 to see if he could incorporate standing into his day and use it more frequently (See Figure 11). Unfortunately, this was not a good fit for him, and he got another Group 3 power wheelchair.

With no stander, after only a year, Daniel's hamstrings and ankle plantarflexors have become significantly tight. It is affecting his sitting position in his wheelchair. He's now headed for possible surgeries that may have been avoided or at least less invasive had he been able to continue a standing program. Considering that he made it to this age before surgery was discussed is a positive thing for sure for him, regardless of the procedures performed.

I'm not saying that standing for Daniel solved all the problems in the world. It could be coincidence that he lost all the motion around the same time he stopped standing. However, based on research evidence, I believe it had a strong affect.

I also need to point out that Daniel maintains a very active and very fulfilling life. With everything in life, people make choices on what is most important. I would never say that Daniel and his family made the wrong choice by

prioritizing activities and sports. I think that he and his family have a great life, and I'm so excited for what he has and will accomplish.

Two very different kids with very different needs. For Lincoln and his family, we are currently able to meet their needs and he is able to stand regularly. That may change as he gets older, but remains to be seen. For Daniel, unfortunately, we were not able to continue to meet his standing needs as he got older. But again, we did not fail in either case. Both families have seen many benefits from standing and both speak positively about their experiences. So good outcomes all around.

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