I AM FORTUNATE TO GO TO WORK AND truly enjoy what I do each day. This satisfaction comes from the challenge of working with unique clients with a variety of diagnoses and problem solving to make outcomes that truly impact each client’s life. I couldn’t do my job without the team I work with: vendors, rehab engineering and peer therapists – physical therapists, occupational therapists and speech language pathologists. This team approach helped achieve each of the following client’s goals with their seating system.

This past summer, I had three young clients with Duchennes muscular dystrophy referred for my services all within a short period of time. Each young man had the hallmark proximal weakness, joint contractions, and postural asymmetries as seen in most clients with Duchennes as teenagers. They also all exhibited limited head and arm control requiring dependence upon exaggerated lumbar lordosis for stability when seated. The progression of each client’s scoliosis and limitation on function varied in severity. None of the clients or family members had previously been educated on the medical complications accompanying these postural changes: difficulty with breathing and speech production, digestion, and skin breakdown. They all understood the discomfort associated with these changes, as this was the primary complaint in all three cases.

Jacob is a 21-year-old college student active with research and nationwide presentations. He is dependent upon his MWD chair with power tilt, recline, seat elevator and laptop computer from lap tray to complete school related activities. Caretakers assist with ADLs and dependent transfers. His wheelchair had no positioning aides with planar back and Roho Quatro cushion unlocked. A flexible S curve scoliosis, flexible pelvic obliquity, bilateral hips abducted in seating-flexible, but causing lateral calf sores were all noted on his mat evaluation. Client and team goals were to address leg position and skin breakdown/vascular issues, back pain, optimize functional use of arms from wheelchair, and energy conservation.

Travis is a 17-year-old high school senior using the same power wheelchair at home and school for functional and recreational activities. Travis’s family assists with self care and dependent transfers. He was pursuing equipment for current use and will also be in college next year. His current wheelchair was an MWD with planar seat and back. Other than chest support for transport, he also had no positioning aids. His posture was fixed with an S curve scoliosis with a mild rotary component and a fixed pelvic obliquity. He was dependent upon anterior trunk lean and arm support for balance to complete writing, feeding, phone use, etc. His endurance to complete such tasks was becoming more difficult in the past year. Family was discussing purchasing an iPad for the applications to decrease difficulty with school work completion. The client and team goals were to address instability, pain in arms and back, optimizing function he was losing quickly, assistive technology options and trial. Travis stated from his first visit he is very resistant to change.

Andrew, an 18-year-old high school student, was using AAC for school work. He plans to attend school into his early 20s. He had limited interaction with staff secondary to difficulty with breath support for speech, pain and probable depression per family. He presented with severe rotary scoliosis and fixed both pelvis obliquity and rotation. His scoliosis caused an anterior lean and a dependence on chest straps to stay in the chair. He had no ability to pressure relief, current and history of skin breakdown buttocks-popliteal fossa-feet elbows, presented with severe pain, multiple bouts of pneumonia in the past year, comprised vascular status of distal legs and very limited use of his power wheelchair at school. The power wheelchair at school had trunk laterals, but no other customized or power features. In the power chair,
significant pain and poor endurance for operating the joystick were reported. His family had brought Andy to the clinic with the goal of a new manual wheelchair beyond current K004 with mild contour back. Neither their home, nor transport option, were accessible for power. The manual wheelchair is a transport chair due to his inability to propel. Family and team goals included pressure relief, skin protection, pain reduction, prevention of and/or decreased frequency of pneumonia, and decrease time bed bound at home.

I worked with three different vendors chosen by the families with these cases, but all with positive outcomes due to our collaboration of ideas, their level of expertise, and also our service delivery model requiring team assessment, trial, through to delivery. Each case took significant education for the client and family on the influence of resting posture on breath support, digestion and wound prevention, as well as the need for repetitive pressure relief. Only Jacob was using tilt for pressure relief and to rest out of hyperlordotic position. Both Travis and Andrew had fixed scoliosis and pelvic deformities, but with appropriate support, we were able to position their trunks more elongated with neither of their ribcages resting on their pelvis assisting. This position in the trial resulted in pain reduction and in the long term for improvements in lung capacity, digestion, wound prevention and increase in comfort.

No off the shelf back support would meet any of these clients’ needs due to severity of scoliosis and trunk weakness. An extensive trial of more trunk support was required to reinforce the benefits of this type. During the trial, functional abilities were tested depending on each client’s active mobility: Jacob – forward trunk lean and reach, Travis – writing samples and self feeding, Andrew – speech production and comfort due to lack of movement other than in his fingers. Cushion trials were also completed, but fixed pelvic obliquities, intact sensation, and wound history for each client led us to the end product. Each individual required different arm rest, drive control set-up and head support equipment.

In each case, a custom molded back support and Roho quatro cushion was utilized on the base that best fit the clients’ needs: Jacob and Travis an MWD power with power tilt, recline and seat elevator; Andrew a manual tilt in space chair. The degree of molding was the critical piece that required skill and follow-up after initial implementation to achieve optimal postural support and pain relief. Both Jacob and Travis were molded from a seated
Comparison of Three Clients
(continued from page 31)

position with a varied degree of support due to available trunk and arm strength, but Andrew was my first client we completed the molding with him supine with legs supported to 90 degrees of hip flexion. His anterior postural lean and lack of trunk and head control led to this technique after failed attempts in sitting. Additional support of an abdominal binder built into back support for positional assist will give circumferential support to Andrew for positioning as well as pressure relief.

All clients had to be educated on initial positioning in system, as well as frequency of pressure relief during molding through to implementation. Each client was pleased with the outcome. Jacob expressed decreased pain with total contact of the system and also increased control of hand placement through a greater range on his lap tray during the molding. He was open to decrease in trunk active mobility with custom versus planar back due to the functional gains as listed. He also expressed the goal of preventing further postural decline with use of the custom back, as well as increased frequency of pressure relief with power options.

Travis had a difficult time adjusting to changes, as he stated he would, but as a team we adjusted fit according to his needs, but were firm in our recommendation out of a planar system. It took his old system breaking down for him to be dependent on a new system and trial for longer than one or two hours. He then admitted he could complete daily living tasks more effectively with less fatigue and pain. He found he could be more independent within this system. His mother reported improved self-advocacy from her son she had not seen previously – important with his upcoming move to college.

Andrew will require frequent pressure relief assistance to prevent wounds on his rib cage, but will be able to spend longer periods at home, out of bed, without a chest harness. I knew success was achieved when this typically morose individual kept smiling during the molding process and with an increase volume of speech noted. During the molding, skin tolerance to the system was assessed twice after 20 minute intervals secondary to degree of asymmetry and projection of his ribs. This
assessment reinforced to his family the need for manual tilt, a choice they were initially resistant to. We also recommended the addition of power tilt with custom seating at school, which family stated they would consider pursuing.

In each case, the team collaborated with the client and family while reinforcing through education and trials the effect seating choices have on overall health and functional activity completion. The expectation was set early that customized seating would require multiple visits to our clinic for fitting and implementation. The team optimized all of our resources with assistive technology needs for Jacob and Travis with rehab engineering plus speech and occupational therapy, and the use of the skills and education of manufacturer’s representative with unique custom molding needs of Andrew.

As a team, we can take pride in the clients’ and families’ satisfaction with the outcomes achieved of increased function and time tolerance to use of the chairs. These cases were also great learning experiences for our entire team: the evaluation and treatment with mild to severe postural asymmetries, and the ability we have with appropriate equipment to take a role in fighting against the destructive postural tendencies associated with Duchennes. I look forward to working with these clients in the future and to evaluate if earlier customized support in situations as with Jacob can prevent the difficulties Andrew has had to deal with.

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