



# JOSHUA: A SLEEP POSITIONING JOURNEY

*Joshua is a 19-year-old with the diagnosis of cerebral palsy. I have worked with Joshua, his caregivers and his team since he was about 3 years old, seeing him periodically as needs arose. Joshua has been positioned in an Aspen Seating Orthosis (ASO) molded seating system for many years. He has a manual tilt-in-space wheelchair and a speech-generating device. He also uses a stander. He is in high school and lives at home with his family.*

## ORTHOPEDIC CHANGES CAUSING SEATING CHALLENGES

About three years ago, Joshua began to have significant difficulties tolerating his seating system. He has extremely high muscle tone, and he appeared to be actively fighting his seating – in particular, he was extending his left hip with significant force and driving the right side of his pelvis down into obliquity. Upon a mat examination, his scoliosis appeared to have worsened quite a bit. His mom took him to see the rehab physician, and x-rays showed that the lateral curve in Joshua's lumbar area had increased from 20 to 40 degrees over six months' time. He had experienced a growth spurt during that time, secondary to hormone injections designed to speed puberty and stop his growth.

Joe Bieganek, ATP, orthotist and president of Aspen Seating and Ride Designs, worked tirelessly with Joshua, his mom and me to address the situation over the last few years. We created a new mold for Joshua, and Joe fabricated a temporary seat

and back to accommodate his orthopedic changes and provide a trial system. We also discussed sleep positioning. We had discussed this before, but Joshua's family had been reluctant to try fearing his quality of sleep would lessen. After this latest mat examination, we knew that unless we addressed his position in sleep, we would continue to have worsening issues in the seating system. His significant asymmetries during sleep were leading

to loss of range and orthopedic distortions that the seating system was unable to keep up with. That is when we found out that Tamara Kittelson-Aldred was coming to Denver, Colorado, to present a two-day course on postural care, and we invited Joshua and his mom to attend.

## SLEEP POSITIONING, PHASE 1

During the course, we reviewed Joshua's current sleep position and status. He had always slept in prone and would choke if placed in supine, even with the head of the bed elevated. He had never slept more than two hours at a time since birth. His typical sleep position included: lateral spinal curve, hip flexion and rotation

(left externally rotated, right internally rotated), head turned to one side (usually to his left) and the left leg flexed at the hip and knee and tucked under the right leg (See Picture 1). As expected, his sleep position reflected his postural tendencies in sitting.

Using some simple components and strategies during the course, the class attendees were able to position Joshua in a much more symmetrical posture (See Picture 2). His parents then worked to duplicate this at home. His mom made a custom pillow which was placed under his trunk to raise him enough to give him more room at the shoulders and allow him to turn his head. His dad made him Plexiglas brackets (these looked like bookends) to support Joshua laterally. The brackets were placed on a non-slip material and then covered with a blanket (See Pictures 2 and 3).

Using the new sleep system, Joshua began to sleep for up to six hours at a time for the first time in his life! He was much more relaxed in the morning, as well. Remarkably, after one month of using this sleep system, he returned to his doctor for repeat x-rays which showed a reduction in the lateral curve of 20 degrees. He also had increased range in the left hip.

## SLEEP POSITIONING, PHASE 2

Joshua's mom continued to revise the sleep positioning system to best meet Joshua's needs. One area that remained difficult to control were his lower legs.



PICTURE 1



PICTURE 2



PICTURE 3

UNFORTUNATELY, JOSHUA WAS HAVING MORE AND MORE DIFFICULTY WITH HIS BREATHING – PARTICULARLY IN SITTING. AS A RESULT, HE WAS SCHEDULED FOR A TRACHEOSTOMY.

His trunk was well-aligned, but he was flexing his knees, and one leg was often crossed over the other. Various components were tried with little success (See Picture 4). Joshua was also beginning to move quite a bit at the junction of his spine and pelvis. Although his sleep system kept his trunk aligned, it was unable to adequately prevent movement at the pelvis as the sleep components were in two different sections – one under the trunk and one under the legs. Joshua was also flexing his hips and pulling back the left side of his pelvis. After more problem-solving, we determined that a one piece molded sleep system was required to prevent movement between the trunk and pelvis and better control his overall posture. An Aspen Seating Recumbent Sleep Orthosis (RSO) was recommended. Picture 5 shows

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PICTURE 4

Picture 1: Joshua's typically sleep position before intervention.

Picture 2: Joshua's initial sleep positioning system in prone.

Picture 3: Joshua's initial sleep positioning system from the side.

Picture 4: Unsuccessful attempt to position Joshua's legs during sleep.

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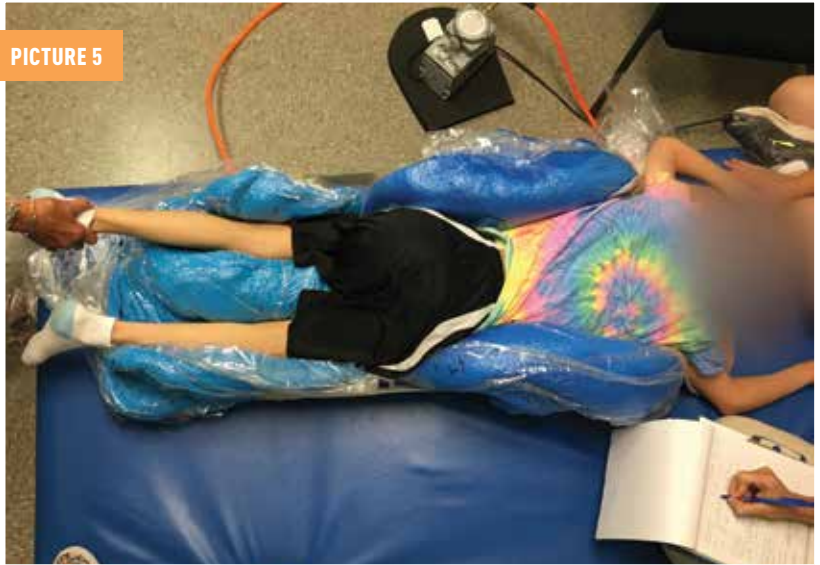
Joshua in the mold for this system with very good alignment and tolerance.

After funding was obtained for this system, the RSO was fabricated and fit to Joshua. At home, while Joshua looked great in the RSO, the family was having some practical difficulties. As he was positioned in prone, getting to the feeding tube was difficult, as were diaper changes. More than one caregiver was required to get Joshua in and out of the RSO – though all of his transfers were becoming increasingly difficult. The family had a portable overhead lift above the bed, but the sling was placed under Joshua in the seating system before transfers and this position did not help move him to prone over the RSO.

Unfortunately, Joshua was having more and more difficulty with his breathing – particularly in sitting. As a result, he was scheduled for a tracheostomy. Chances were that, after surgery, he would no longer be positioned in prone and so would be unable to use the RSO. During his hospitalization, his mom used her training in postural care to support Joshua in supine with the head of the hospital bed elevated. She used the non-slip material to help prevent Joshua from sliding down in the bed. She also used swim noodles covered in Coban wrap (to prevent slipping) and placed these on either side of Joshua's trunk to keep him aligned.

Joshua is just coming home from his surgery. He is breathing much better, and he is sleeping in supine with his head and trunk elevated for the first time in his life (See Picture 6). We will have to dig in again and problem solve how to support him in this new orientation, so he is as well-aligned as possible.

PICTURE 5



Recumbent Sleep Orthosis shape capture.

PICTURE 6



Sleep positioning in supine, post-surgery.

Sometimes sleep positioning solutions can be straight forward and effective. In Joshua's case, nothing is straight forward, but sleep positioning has made a difference and is key to limiting further range loss and orthopedic changes.

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