Sleep is such an important part of health. It allows for muscle repair and the release of
hormones that regulate growth and appetite. In addition, adequate and quality sleep
contributes to a healthy immune system as well as consolidation of memory. A
complete sleep cycle lasts, on average, between 90 and 110 minutes.

People with cerebral palsy are at increased risk for sleep problems. These problems are more
pronounced when dystonia is present. When dystonia compromises the child's airway,
breathing can become a fight for survival. The involuntary muscle contractions that are so
typical of dystonia can affect the muscles of the neck and consequently occlude the airway,
disrupting sleep. This airway occlusion was a very real concern for one particular family. Their
daughter, Susan, experienced a difficult birth and post-natal course. Consequently, Susan was
diagnosed with spastic quadriplegia with dystonia in addition to other comorbidities. Susan had
always experienced difficulties with safe and adequate position during sleep. She would extend
and rotate her neck to the point that her airway became compromised. Her mother, Karen,
shared that she slept with Susan every night for the first thirteen years of Susan's life. In her
effort to secure restful sleep for both mother and daughter, Karen tried melatonin drops,
aromatherapy, white noise machines, lullabies, massage, and many other remedies. Nothing
seemed to work, and Karen and Susan were both constantly exhausted.

The family lived in Germany when Susan was younger, and she received Bobath therapy.
Instruction in *handlung* (handling) by the Bobath therapists, as well as Susan's mother's
background as a ballerina, made her realize the importance of good alignment to promote
safety and relaxation during sleep. Susan's mother used her own body, and different sizes and
shapes of rice bags (which absorb and maintain body heat) to maintain and monitor adequate
alignment of Susan's head and neck, as well as her trunk and lower extremities, when she was
sleeping to prevent anoxic events.

When Susan was admitted to residential care in 2003, the team had to come up with a solution
that would be safe, providing Susan with much needed sleep. The team, which included
occupational and physical therapists, a rehabilitation and medicine physician, as well as the department of assistive technology, evaluated the options available. Initially, Susan trialed a side lyer, requiring rice bags inside foam to prevent significant cervical hyperextension. However, this positioning option did not provide her with a soft enough support for her trunk and extremities, nor a firm enough support to maintain head and neck alignment. Repositioning required two staff members and would invariably wake Susan.

In 2004, Susan was hospitalized after she suffered an anoxic event. She was admitted to a major children's tertiary care center. Even though she recovered well, her spasticity increased. When she returned to residential care, it became even more apparent that Susan needed a positioning system to sleep safely.

FDA and state regulations and guidelines are very specific regarding bed safety for people in residential care. To remain in compliance with these regulations, the assistive technology department found and ordered a commercially available bed positioning system for Susan that met those requirements.

The sleep positioning system has the flexibility to slide block supports from one side of the bed to the other within linear tracks, allowing supports to be positioned at varying points along her body. These supports were easily removable so that Susan could be turned at night with minimal disturbance to her sleep. The supports could also be adjusted to accommodate for growth.

Susan presents with a dystonic pattern that is initiated by neck extension and rotation to the right. This is followed by trunk extension, scapular adduction and elevation, and shoulder adduction with elbow flexion. Therefore, the flat system head support did not provide adequate support to maintain head, neck, and upper trunk alignment. The assistive technology department adjusted the original head support by making it wider and building in a curve in which her skull could rest, decreasing her ability to extend and rotate her neck. The adapted head support provided sufficient support for a few years. In 2012, Susan was hospitalized for pneumonia and unfortunately suffered medication-induced cardiotoxicity, which changed her spasticity, as well as the severity of her dystonia. Upon her return, the team realized that Susan required additional support at her shoulders to maintain effective and safe positioning. Another support was added to promote protraction of the scapulae, which promoted relaxation of the
shoulder girdle and neck musculature.

The system with modifications is still in effect 12 years after it was initiated, and Susan is able to sleep well and comfortably at night. The team approach was crucial to assist with problem-solving, trialing different designs, adapting a head support, and manufacturing a scapular support. The adaptations made by the assistive technology team provided Susan with supports to sleep well-positioned and safely at night. Sustained sleep was gained by providing Susan with external supports to maintain a position that she is unable to attain or sustain by herself. Sustained sleep has also improved her general well-being and health, increasing her ability to participate in her life with energy and joy. With the knowledge that Susan was positioned well and safely at night, her mother, Karen, could also get much needed restorative sleep. Karen's words reflect the impact of this journey on their lives. "If Susan and I can help another family, we are willing to share our story." The team is thankful for Karen's continued support and her generosity in sharing her story to benefits other families who struggle with similar difficulties.

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Susan's mother lives and teaches dance in Westchester County. She is grateful for the
health and happiness Susan enjoys from her specially adapted bed and the care she receives at TCDF.

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References

