



Case Study: Emma's Story

Emma is a 7 year old who lives in Utah with her mum Jaclyn, dad Brandon and big sister Ava. She was born with a rare disorder called Lissencephaly, whereby whole or parts of the brain appear smooth and do not have the 'grooves' or 'folds' of a typically developing brain - <https://rarediseases.org/rare-diseases/lissencephaly/>

Emma also has a diagnosis of Epilepsy and Cerebral Palsy, and is affected by seizures, spasticity and weakness throughout her body. She depends on 24-hour care from her loving family, but with their support she can participate in many of her favourite activities. She loves attending school daily and seeing her friends, or splashing in the water with her family during swimming therapy, or dancing and listening to music with Ava whilst using her standing frame.

Standing has been a difficult task for Emma in recent years due to her lower limb contractures and then complex double hip surgery in July 2021. Post-surgery, she required a standing frame that could accommodate the length discrepancy in her shorter left lower limb and provide gentle and supportive hip abduction positioning, whilst still appropriately support her head and trunk and accommodate any contractures still present in her lower limbs. After trialling other standing equipment, eventually Emma, her family and her therapist found one that met her needs perfectly – the Standz 2 by Jenx!

See the review of the Standz 2 from Emma and her mum Jaclyn's perspective:

https://www.instagram.com/reel/CjMCpA5JcIG/?utm_source=ig_web_copy_link

https://www.instagram.com/reel/CjMMDyRpcBN/?utm_source=ig_web_copy_link



With the Standz 2, Emma can now view her environment from a different perspective and play eye to eye with her sister. It enables an important change of posture and a break from prolonged periods of sitting. Some studies have suggested that transitioning from a seated position to standing with supportive equipment may amount to the accumulation of light physical activity in children with similar functional levels to Emma [1], so the Standz 2 can offer that opportunity to interrupt sedentary behaviour that we know is associated with poorer health [2].

1) Verschuren, O. et al. Muscle activation and energy-requirements for varying postures in children and adolescents with cerebral palsy. J Pediatr. 2014; Nov; 165(5):1011-6.

2) Smith, B. et al. Physical activity for general health in disabled children and disabled young people: summary of a rapid evidence review for the UK Chief Medical Officers' update of the physical activity guidelines. Department of Health and Social Care: London, UK. 2022. Available at <https://www.gov.uk/government/publications/physical-activity-in-disabled-children-and-disabled-young-people-evidence-review/physical-activity-for-general-health-benefits-in-disabled-children-and-disabled-young-people-rapid-evidence-review>. [accessed on 05.09.2022].

The tray, shoulder protractors and elbow blocks on the Standz 2 help keep Emma's upper limbs towards midline which can be important for play and interaction. The individual leg posts with individually adjustable knee supports and foot plates allow for comfortable and accurate support of her leg length discrepancy. The innovative hip abduction feature ensures appropriate positioning that may be beneficial for maintaining hip stability and range of motion in the developing hip, particularly after surgery [3,4].

Emma's Mum Jaclyn reports that she 'loves' Emma's new stander, it is complimenting Emma's daily routine and intense therapy she is currently receiving. She is noticing Emma gain more strength in her neck control and trunk. Jaclyn has also noticed Emma 'seems happier with less seizure activity and more engagement'.

Emma, Standz 2 and the ICF/F-Words [5,6]

Fitness

(Body Structure & Function)

Standing and weightbearing is associated with a raft of positive health outcomes that will be beneficial to Emma – maintenance of hip stability, improvement of bone density, accumulation of light physical activity, aiding cardiovascular and respiratory function to name but a few.

Functioning

(Activity)

The tray, shoulder protractors and elbow blocks on the Standz 2 assist with play and upper limb function in midline for Emma. The trunk and lower limb support ensure she can safely focus on developing her head and upper limb strength.

Friends

(Participation)

Standing enables Emma to benefit from eye to eye interaction and play with her sister and peers.

Family

(Environmental Factors)

The Standz 2 fits perfectly into the home environment. The frame has a perfect height for supine positioning and transfers and its ease of use ensure there is no added stress to the family daily routine. Emma's parents love her new stander and are so happy to her standing again.

Fun

(Personal Factors)

Emma loves to dance and play with sister in her standing frame. Mum Jaclyn reports that Emma feels proud when she can take part in all of her therapy and loves moving her body in a safe and supported manner.

Future

The Standz 2 will continue to be an important aspect of Emma's 24-hour postural care and movement programme. It will continue to aid participation in activities, play and interaction, as well as helping to prevent further complex lower limb surgery.

3) Martinsson, C., & Himmelmann, K. Effect of weight-bearing in abduction and extension on hip stability in children with cerebral palsy. *Pediatric Journal of Physical Therapy*. 2011; 23 (2), 150-157.

4) Martinsson, C. & Himmelmann, K. Abducted Standing in Children With Cerebral Palsy: Effects on Hip Development After 7 Years. *Pediatr Phys Ther*. 2021; 33(2), 101-107.

5) World Health Organization. (2001) International Classification of Functioning, Disability and Health (ICF).

6) Rosenbaum, P. & Gorter J. The 'F-words' in childhood disability: I swear this is how we should think! *Child: care, health and development*. 2011; 38(4): 457-463.

For more information visit the
F-Words Knowledge Hub: www.canchild.ca/f-words

