



Case Study: Penelope's Story

Penelope is 6 years old and lives in County Cork, Ireland, with her mum, dad and 3 younger brothers. She loves going to school to see her friends, watching her favourite TV shows at home with her family and, according to mum Katie, has had a 'life-long infatuation with Elmo from Sesame Street!'

Penelope has a rare condition called Pontocerebellar Hypoplasia (<https://rarediseases.info.nih.gov/diseases/10977/pontocerebellar-hypoplasia>), associated with CASK gene mutation (<https://www.ncbi.nlm.nih.gov/books/NBK169825/>). This condition causes underdevelopment or degeneration of the Cerebellum and Pons, areas of the brain which support many functions including maintaining balance, coordination of movement, breathing and swallowing.

Penelope struggles with purposeful movement and needs whole body support in all positions to help her participate in daily activities. Over the years, Penelope and her family have particularly struggled to find appropriate adaptive chairs that could support her needs and still enable involvement in home and school activities. Thankfully, two seating systems made by Jenx have been there to provide this support, growing with Penelope along the way: **The Atom and Junior+!**



During pre-school years, Penelope had the helping hands of the Atom, before transitioning to the Junior+ as she grew, ensuring she had familiar and appropriate seating support as her posture and skills developed.

Scan the QR code or follow the link to understand how Atom has benefitted a young boy called Lucas: <https://jenx.com/40stories-lucas/>



Both chairs have enabled Penelope to sit safely and securely whilst playing and interacting with the environment around her. Katie says: **“I can’t tell you how valuable that is. Families might take for granted how easy it is to allow your child to sit independently and play at home whilst you focus on other tasks or take time to yourself as a parent. I don’t think anyone would naturally get excited by specialist equipment, but the happiness and security that we felt when we got an adaptive seat into our home, we really can’t explain”**. Penelope and her family love her Junior+ chair so much that she now has one for home and one for school! The Junior+ is there to support Penelope through so many activities during the day – playing with friends at school, watching Elmo on the TV, eating dinner with her family at the table and, even for haircuts!

Katie said: **“I’ve never been able to take Penelope to the hairdressers due to the support she needs – but haircuts can now be safely done in her Junior+ chair at home thanks to its postural support and easily adjustable headrest, which can drop down and out of the way. This is so much more than just a chair and tray – it helps in so many aspects of her life”**.

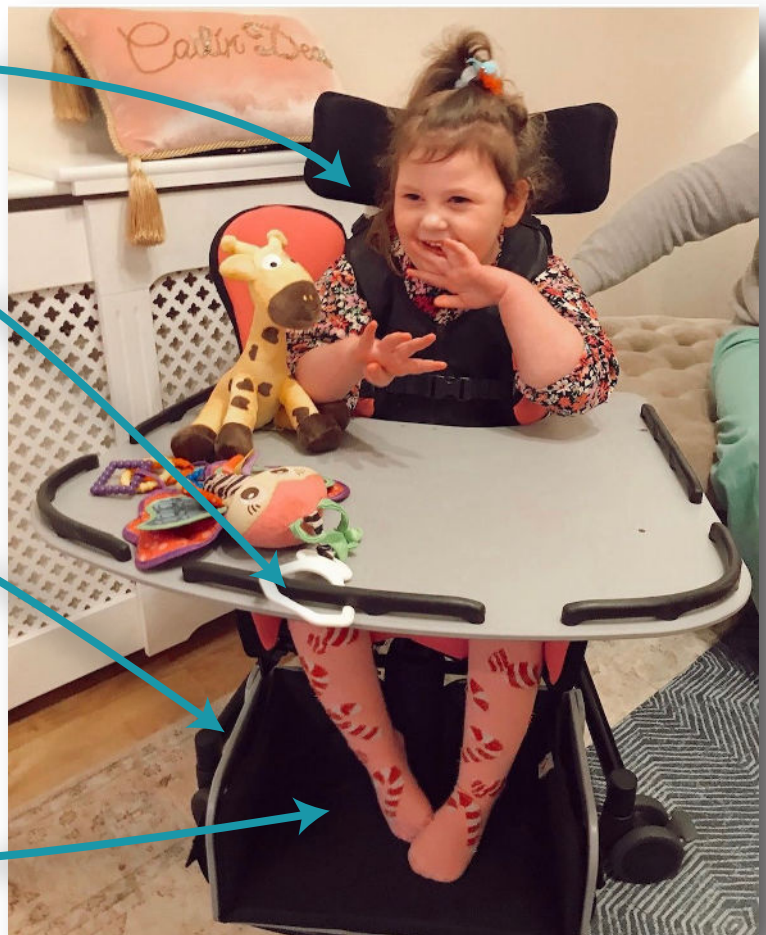
Here are some features of the Junior+ that help support Penelope’s posture and daily activities:

The easily adjustable and tool-free shoulder protractors help encourage midline play with Penelope’s favourite toys and help develop upper limb skills.

The tray edging allows Penelope to attach her treasured butterfly clip to the chair, ensuring her favourite toy comes with her wherever she goes. Katie loves the tray edging and said **“toys rarely fall off the table and Penelope is able to enjoy meaningful playtime independently”**.

The high-low base has been essential for play and interaction – it goes low enough for floor based play with friends and high enough for the family to sit together at the dinner table. Penelope’s parents are both very tall and the high low-base has also been essential for supporting administration of medication and feeds through her PEG tube, reducing strain on their lower backs.

The padded footbox allows Penelope to have freedom of movement within a safe space in her lower limbs whilst sitting – providing her with essential sensory feedback and active movement, and reducing sedentary behaviour.



Fitness

(Body Structure & Function)

The Junior + provides optimal support to create a stable and symmetrical posture that allows for reduced energy expenditure. It helps to avoid prolonged 'destructive' postures that may affect internal functioning and lead to musculoskeletal abnormalities. It encourages active sitting and play that will help build Penelope's stamina and reduce her fatigue.

Functioning

(Activity)

Features such as the shoulder protractors, leg guides, hip guides and tray help to create a stable and active posture to allow for development of upper limb skills and play.

Friends

(Participation)

Penelope can sit and play safely with her friends at school – playing at floor level or table height with the high-low base.

Family

(Environmental Factors)

The impact of both the Atom and Junior+ has been profound. They have greatly reduced the care burden, enabling opportunity for safe and independent play for Penelope but also independent time for her parents. The Junior+ continues to enable Penelope to participate in many family activities at home.

Fun

(Personal Factors)

Penelope can play with her toys meaningfully without them regularly falling off the table, and can safely watch her favourite Elmo shows whilst actively kicking her legs!

Future

The Junior+ will grow with Penelope and support her for many years to come, continuing to help her to develop her skills and providing optimal postural care.

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

2) 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): 457–46

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

