



Spex as part of 24/7 Posture Care Management: Illustrative Case Study

In February 2020 I met Jesse and his family during a Spex backrest handover and set-up. What struck me most about Jesse was how his 24/7 posture care management routine was so carefully followed and monitored to maintain his engagement in activities he loved, whilst preserving and protecting body shape since his childhood, following a diagnosis of Cerebral Palsy.



It was, for me, a great success story; all the pieces seemed to slot into place and routines were well established. In my experience I know that it takes much work and buy-in from all parties involved and well-coordinated interventions to achieve this 'success', which is often marked by many challenges along the way.

In Jesse's case, his person-centred care and 24/7 posture management was comprised of:

- Multiple interventions from his childhood to his adult years,
- Resilience in the face of adversity,

- Many different positioning products for lying, sitting and standing postures,
- Many therapists' involvement along the continuum of services from paediatric to adult years,
- Many challenges and fierce advocacy of Jesse's functional and quality of life goals,
- A total commitment by family and caregivers to follow recommended strategies and postural management guidelines to support Jesse's posture to date.

Please note:

This article was written with full consent and input from Jesse's mother from the perspective of the family. His direct care-team have not been included and therefore there may be additional points not identified. Clinical opinions expressed are my own. Clinical references are included.

Background to terminology:

Posture is defined as the body's ability to (Pope, 2007, p. 21):

1. Conform to the supporting surface
2. Organize balance and stabilize body segments in relation to the supporting surface
3. Adjust to disturbances within and outside of the body (biomechanical forces)
4. Secure a fixed point around which muscles can act – think 'proximal stability for distal function'.
5. Offload the body segments required for movement
6. Adopt the most appropriate arrangement of body segments for performance of the task at hand.

Posture is acquired over many years as the child develops and this learning can be disrupted by clinical conditions affecting development, neurological function, or skeletal changes.

24/7 Posture care management is not a new concept, with many contributors to the development of the approach (Fulford & Brown, 1976; Pountney, Green, Mulcahy, & Nelham, 1999; Pope, 2007). Definitions include 'management' and 'care':

1. Postural management, which can be defined as “planned approach encompassing all activities and intervention which impact on an individual posture and function ... tailored specifically [to the user]... may include special seating, night-time support, standing supports, active exercise, orthotics, surgical interventions and individual therapy sessions.” (Gericke, 2006, in Robertson et al. 2016), and
2. Postural care, which encompasses “...all the individual components of postural management programme ... a way of preserving and re-establishing body shape for people with movement difficulties.” (RCGP, 2012)

Posture care management is a long-term intervention. The first point draws focus on the **'what, where, when, how'** but the second point better highlights the **'why'**, in my opinion. Clinicians know that to minimise complications relating to postural deformity, we want to protect and restore body shape. We also want to ensure that we offer optimal support to the trunk to facilitate increased control in the arms (Yildiz, Yildiz, & Elbasan, 2018). In order to do this, we need to consider sitting, standing and lying postures of the individual:

- “The pelvis is the keystone of the body structure,” (Pope, 2007, p. 113) and requires first consideration when looking at the seating system. A stable position in seating and the correct alignment and support of the trunk allows the head to be optimally orientated in space and for improved function of the arms.
- Standing helps to maintain tissue length, maintain bone mineral density and maintain muscle mass in individuals with immobility and “building a stable posture in standing is integral to the overall physical management of the disabled person with severe and complex disability.” (Pope, 2007, pp. 132-133)
- Inability to change position, postural asymmetry and spasticity are indications for support in lying and failure to address night-time positioning prevents the ability to modify secondary postural complications (Pope, 2007, p. 105).

The postures we assume throughout the 24-hours in a day, need to be part of a posture care management programme. Success depends on the correct identification of equipment needed to meet the clinical and postural needs, and the timely intervention by the multi-disciplinary team, including the family and caregivers and a shared understanding for a truly person-centred care approach (Person-centred Care, 2017). This must also consider long-term management and review of equipment, posture, interventions and routines when circumstances or the individual's condition changes.

Spex seating technology falls within the categories of assistive technologies and complex rehabilitation technologies which are defined as follows:

- Assistive technology is “any item, piece of equipment or product system whether acquired commercially off the shelf, modified, or customized that is used to increase, maintain or improve functional capabilities of individuals with disabilities.” Public Law (PL) 108-364 the Assistive Technology Act of 1998, as amended (2004) as cited in (Cook & Polgar, 2007, p. 5).
- Complex rehabilitation Technology refers to “medically necessary, individually configured devices that require evaluation, configuration, fitting, adjustment or programming ... designed to meet the specific and unique medical, physical and functional needs of an individual ...[requiring]...the clinical component [and] the technology-related component...” (NCART, n.d.)

Spex seating technology provides a commercially available off-the-shelf product that is modular and can be customised to the persons unique body shape in order to preserve and restore body shape in sitting. It is also responsive to the specific and unique functioning of an individual within a seated position. The Spex seating technology can be used on strollers, buggies, manual wheelchairs and powered wheelchairs to provide postural support in sitting.



As versatile and adaptable as it is to changes in body shapes and the potential to use the seating technology system to reinforce support, preserve or restore body shape, it cannot be considered in isolation within 24/7 posture care management.

Jesse's background:

Childhood years:

Jesse was born in 1991. His parents were told he had severe brain damage, spastic quadriplegia and cortical dysfunction, cortical blindness and mental retardation. He was supported to attend a therapeutic environment once a week where he worked with Speech and Language Therapy, Physiotherapy and music teachers.

When he was 4 years old his family learned of 'conductive education' (CE) which is “based on a 'simple' concept of human potential; meaning that everyone has the capability to learn and develop irrespective of their starting point.” (NICE, 2018) and designed for children with neurological and motor disorders (Cerebral Palsy and

Conductive Education, 2020). His mother reported that this was not a familiar intervention and that she came to hear of this via another mother but sought this out to best optimise Jesse's learning and skills achievement. She recalled this programme being very intensive, a novel approach and time consuming. It entailed attending groups where Jesse would be out of his supported wheelchair to develop postural skills. It required a significant level of involvement from his parents, who would continue the programme at home.

During this time Jesse also had attended Kindergarten with a 1:1 teacher aid once a week; Kindergarten was an opportunity for Jesse to socialise in a different environment and make friends away from his family.

Participating in CE continued until he was 5 years old but was discontinued due to his increased extensor thrust pattern of movement. It was around this time that the family also learned that he had the diagnosis of Cerebral Palsy, rather than the multitude of presentations they'd been told in the earlier years.

Jesse's condition means he is non-verbal, and communication requires a great deal of familiarity with his behaviours and expressions.

Teenage years

His mother reported that these years were particularly challenging. His exercise programme was no longer effective, and Jesse presented with increased spasticity and contracture development. He required surgical intervention to release tendons in his hand/wrist and hips (requiring a hip Spica cast, which included its own set of challenges for care and positioning), and shortly after this he began to develop scoliosis. Scoliosis can lead to difficulties with caregiving and prone-lying, standing and supine lying are part of a postural management programme (Scoullar & Imms, 2010).

Spinal rod surgery was considered to better align the spine, and his family commenced a rigorous programme in conjunction with the multi-disciplinary team. The exercise programmes were reviewed, assistive technologies in use were reviewed and adjusted to his new needs and a sleep system for positioning in bed was introduced.

Jesse's extensor thrust force contributed to failure of assistive technologies as he got older; he broke the back posts of a wheelchair when he was 12 years old with the repeated force of his extension in sitting. His postural considerations required careful need to review the robustness of equipment selection for shower chairs and wheelchair chassis to ensure that the technology best met his needs whilst allowing function and mobility.

Jesse attended school at a regular high school with a unit that could cater for his needs, until he was 13 year's old. Thereafter he was placed in a class with other children with various disabilities. This posed additional challenges considering Jesse's response to loud noise and behaviours exhibited by other, more mobile, children. Jesse was taken out of school when he was 19 years old.

Jesse had a well-developed routine in his teenage years. He went swimming, he met with friends once a week, he attended school, he had a postural management programme that consisted of prone lying (lying on his stomach for participation, tone management and slowing further loss of range of movement), standing in a standing frame, wearing ankle-foot orthoses, wearing arm and hand splints to reduce the risk of contractures, and maintaining a strict personal care, exercise and night-time routine.

Adult years

He developed dental problems when he was 19 years old, from impacted molars. He needed repeated courses of antibiotics and presented with increased salivation and choking, which impacted on his feeding. The challenge of providing person-centred care in a coordinated fashion became evident as Jesse's mother recounted their wish to pay privately for dental procedures required, but not being able to do this because of the process of referral through the public health system, which took over a year for surgery to be scheduled.

Whilst waiting for the dental surgery, Jesse's medication was changed to manage infection and minimise increased salivation. which consequently led to medication changes to manage the increased oral secretions. The medication changes resulted in persistent episodes of diarrhoea, which was felt to directly contribute to skin breakdown over his bottom. Moisture can contribute to skin breakdown by causing maceration, which predisposes skin to injury (Bhattacharya & Mishra, 2015). This impacted on sitting tolerance, sitting and lying positioning, functional activities he routinely engaged in and, again, required a review of his established routine and existing assistive technologies used.

- His bed was assessed, and a dynamic air mattress prescribed to ensure good pressure distribution to alleviate the skin breakdown. In Jesse's case this is reported to have caused increased sweating.
- Swimming was discontinued.
- Any environments that may result in picking up an infection were avoided.
- Time spent in his wheelchair was limited to 1.5 hours maximum and he spent more time in his bed.

When Jesse was 21 years' old spinal rod surgery was no longer indicated. Although he continues to present with scoliosis, pelvic obliquity, pelvic anterior tilt and pelvic rotation, the approach to his posture care management avoided further postural deterioration to the extent that surgery would be required.

Appreciating the risk of caregiver burden:

With one parent requiring to be a full-time informal caregiver for Jesse, limited extended family support, and additional children to look after, it was evident that Jesse's childhood years were challenging to the family.

As a clinician working predominantly with adult and elderly populations, I am familiar with the caregiver burden experienced when a family member suddenly needs to assume the role of caregiver in short-/long-term – these are indeed well described in various texts (Given, Given, & Sherwood, 2012; Hildebrand, 2016; Lindenberger & Meier, 2013). Jesse's mother is recognised as a formal caregiver or healthcare assistant for weekends – this can mean a shift in occupational balance and working long hours ((RanehoV & Håkansson, 2018).

With Jesse's mother's recollection of these challenges it highlighted that the risk of caregiver burden was present throughout Jesse's life. Indeed, Cerebral Palsy is a life-long paediatric disability and caregivers are required to play an essential and key role within the multi-disciplinary team approach and rehabilitation (Dambi, et al., 2016) whilst still having to balance home, work and social life. Financial concerns, limited social support systems, maintaining life roles and the family unit, variable access to information and education about the diagnosis and interventions and a multitude of clinical team members throughout Jesse's lifetime meant that there were certainly challenges.

Jesse's mother said something that continues to echo: **“If you don't have the choice, is it resilience?”** She did, however, highlight that the family coped by taking small steps. By focusing only on 'now' and 'next week', they managed. Working together, keeping things as “normal as possible” and finding shared interests that they could do as a family, and maintaining participation in these interests, were also ways that the family coped.

They applauded the opportunity Jesse had to go to school, as this was the environment where he was able to show off and develop his personality. The importance of familiarity with Jesse to interpret and understand his behaviour was essential and something that was identified early on. Jesse's parents have challenged, questioned and remained a staunch advocate for Jesse's wellbeing. They highlight to me the importance of a shared understanding being critical to the implementation of any therapeutic programme and the acceptance of any equipment needed to support the disabled individual.

The introduction of formal caregivers also allowed his parents to resume their regular tasks that needed to be completed and allowed periods of respite, adding a further dimension to his social milieu.

In 2015 Jesse's mother was diagnosed with breast cancer and required surgery and the support of the formal caregivers was crucial during this time period.

Secondary complications and their impact on posture care management

His 24/7 posture care management plan required reassessment and review with the development of skin breakdown. After approximately six months of persistent, but not deteriorating, skin breakdown, a Wound Care Specialist assessed Jesse and conducted pressure mapping in supine lying (i.e. lying on his back). It showed that Jesse maintained contact only on the back of his head, shoulder blades (scapulae), sacrum and back of his heels. With limited contact along his body, this increased pressure over points of contact and creates an unstable posture. This could be termed a 'preferred posture' (habitual) (Agustsson, Sveinsson, Pope, & Rodby-Bousquet, 2018) and translated into his sitting and standing posture as physiological adaptation had occurred.



Figure 1: Visualisation of reported posture in supine lying

An Occupational Therapist also reviewed his mobility equipment: the standing frame and wheelchair. Key considerations for pressure injury management in seating assessments include: seat width, seat depth, chair seat height, chair back rest, chair seat to back angle, arm rests, leg rests and foot plates, head rest and accessories to support posture and prevent sliding/shear in the seating system (Stephens & Bartley, 2018)

Changes were implemented for his 24 hours posture care management routine:

Standing:

- A new standing frame was provided to better support Jesse's standing position now that he'd grown taller and required a review of the existing support.

Sitting:

- A custom foam cushion was provided following pressure mapping in sitting to ensure optimal pressure distribution, stability of the pelvis and support to the thighs.
- A Spex classic backrest was introduced to ensure optimum contact with Jesse's back in the wheelchair and configured to fully respond to his individual body shape and offload pressure over bony prominences (scapulae) with the addition of a supracor layer for improved thermoregulation.
- Spex lateral trunk supports were provided to reinforce support in

the seating system and best align the trunk for head position and control.

- A Spex headrest was provided that could respond to his unique head position and continue to allow him the ability to move his head and look around. His head position was maintained in midline with the correct pelvic and trunk supports.
- Spex accessories were included for improved postural support and control: a 4-point pelvic support belt, ankle supports.
- The wheelchair chassis continued to include tilt for pressure and fatigue management.
- A PB/DB thoracic harness was used to support the trunk position, whilst still allowing arm movement.

Lying:

- The dynamic air mattress on his bed was removed and a more stable foam mattress was provided.
- A night-time positioning system (Symmetrisleep) was introduced to optimise alignment and provide the necessary support for stability. With this system on his profiling/adjustable bed, he was able to assume a more 'seated' position to ensure greater stability and better contact with the body when lying on his back. This helped to reduce pressure over the area of skin breakdown.
- His bed sheets were discarded and replaced with 100% cotton sheets to reduce his sweating and discomfort.
- Jesse continued with prone lying over a wedge on the floor to completely offload any pressure on the broken area on his bottom and to continue with his exercise and range of motion management programme.

The area of skin breakdown took approximately 18 months to heal and required a dedicated and structured management and monitoring programme. With the addition of the dental treatment required and the postural management changes, including Physiotherapy review of his exercise programme, Jesse has not had any further skin integrity complications to date.

Fast forward to 2020:

Minor changes and reviews had taken place with his assistive technologies for lying, sitting and standing postures, but his postural programmes have continued. Changes have been:

Environmental adaptations to:

- Accommodate the equipment Jesse requires as part of his 24/7 posture care management,
- Facilitate better and easier access to the bathroom, bedroom and shared living spaces easier,

- Ensure space for formal caregiver team.



Image 1: new bedroom layout with overhead hoist, profiling adjustable bed and standing frame

Bed reviews:

- He continues with the night-time positioning system 20 years later and sleeps well with the cotton sheets and stability offered in the positioning system.
- His mattress has been changed to another foam mattress and there has been no return of skin breakdown
- He continues with his prone-lying programme



Image 2: Jesse's mother demonstrating prone-lying

Wheelchair reviews to:

- Include the Spex lateral support comfi covers so family and caregivers can easily release the locking mechanism before transfers.
- Adjust the head rest position and adjust shaping in response to Jesse's postural needs.
- A replacement of the Spex back support with unique contouring to his current body shape.
- Using L-shaped metal brackets to ensure the cushion is maintained in its position when Jesse is using the full force of his extensor thrust when in the wheelchair.

- Provide a sunshade so that Jesse can attend his car racing events with family and caregivers which he loves and get outdoors.

Personal care equipment:

- Review and updates to shower commode chairs
- Overhead hoist provided for more transfers

Standing frame review:

- This has again been updated and standing tolerance was reported to be an hour in recent months. This is an improvement to standing tolerance.

Orthotics reviews:

- Jesse continues with his hand splints, arm splints and ankle-foot orthoses.



Image 3: Arm splints as part of 24/7 posture care management

Prior to 2015 the family had limited holidays or time away from home, but with the introduction of a regular formal caregiver team and equipment that can be transportable, this has allowed the family to plan activities away from the home. The planning and organisation of trips away is time consuming, as his mother described, however this has become part of maintaining a routine that adds to the family's quality of life. They have travelled to see car racing across the country, which Jesse continues to love.

Jesse's social milieu has expanded with the provision of appropriate assistive and complex rehabilitation technology. Equipment, however, can break. It is not possible to always have two of everything should this occur outside of working hours or on weekends, but this has also encouraged "excellent planning." His mother reported that this also means that families and caregiver teams need to, "become crafty ... think outside the square ... and have a lot of vigilance" to continue to maintain routines, equipment, activities and functional engagement.

Caregiver burden risk is present, but mitigated by their approach as a family unit, support of a dedicated Care Coordinator for Jesse's

clinical management and five days of formal caregivers to support the family. This ensures that routines, posture and equipment is monitored, and established posture care management programmes persist. Jesse regularly goes to pub quizzes, meets with his friends and their caregivers for a community-based activity, spends quality time with the family and regularly accesses the wider community.



Image 4: Wheelchair sitting viewed from the front

Image 5: Jesse's current back shape in sitting

Conclusion - reflections

24/7 posture care management requires a team approach, a shared understanding of postural needs, a coordinated and empowering approach, so that interventions and programmes are truly "person-centred" (Person-centred Care, 2017).

In my experience, there are multiple challenges to implementing a robust programme for postural management. These can include funding issues, achieving that 'shared understanding' by the clinical teams and the family, access to carer support and family support in implementing postural care programmes, accepting assistive technologies recommended and obtaining timely review of posture and products when circumstances change. Anecdotal experience by Pope (2007) identified that lack of space for equipment, lack of time or assistance, and potential refusal of people to have 'medical equipment' in the home environment can result in standing programmes for postural management to be less likely in the home environment.

The Spex seating technology components have been effective over the past 20 years to respond to Jesse's pressure and postural needs in conjunction with his other prescribed assistive technology. The back support allows for easy adjustment and configuration, Jesse's trunk is optimally aligned against gravity with excellent contact against the back and seat surfaces for stability and pressure distribution, and his head is well supported on the head rest. Choice of modular components have been prescribed to meet his clinical and functional

needs, as well as the functional needs and ease of the caregivers, so that he can continue to engage in the wider social milieu in his seating system.

Jesse's story is not without challenges. His development of spasticity and contractures, the breaking of needing equipment due to tone and the 18 months of sacrum skin breakdown all required a change in postural care management and assistive technologies prescribed. This case study highlights that even small changes in clinical presentation can have significant impact on daily life for the equipment user and the family involved and that a holistic and person-centred approach is possible to achieve positive functional outcomes.

- Be aesthetically pleasing and allow for self-expression of the wheelchair user.
- Be appropriate for either manual or powered wheelchair chassis.



Image 6: Contact maintained against the Spex classic back support and head support.

Spex as part of 24/7 posture care management

Equipment prescription is based on the clinical and functional needs of the user. It is evident that the Spex back support, lateral trunk supports, accessories and head support have been able to respond to clinical and postural changes over the last 20 years of Jesse's posture care management programmes. Spex can be effective at:

- Providing appropriate postural support for head position and control.
- Providing appropriate pressure relief and comfort for complex posture care management.
- Supporting the body to maintain a healthy alignment against gravity.
- Allowing for adjustment and adaptation as needs change.
- Facilitating engagement in functional activities and facilitating inclusion in the wider social milieu to reduce social isolation.
- Be easy to use by client and family/carers following education and training.

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