



Managing progressive disorders

Many people need assistive products to help overcome physical, mental, or 'behavioural' impairments. For many people these impairments are not the same from day to day, or even from hour to hour. This can be particularly true for those with neurological or neuromuscular disorders. What can we do to help?

When we consider the populations, especially amongst the paediatric and younger adult age ranges, who have mobility restrictions and require wheelchairs, many of these are people who have had developmental brain injuries occurring before or after birth, or people with neuromuscular disorders.

Many of these latter disorders are genetic, and therefore can present from a very young age. They also tend to be progressive in that the individuals' functional abilities reduce over years and months as they increasingly lose muscle control, and therefore need even more intervention over and above that needed as a result of a child's normal growth process.

Children born with progressive neuromuscular disorders such as a muscular dystrophy (MD) or spinal muscular atrophy (SMA) require an increasing range of specialist equipment as their condition progresses. This can include a wheelchair for mobility; special seating to provide postural support for the pelvis, trunk and head; and a standing frame to counteract the effects of prolonged sitting.

Time spent in standing equipment can improve upper limb, respiratory, and digestive functions, as well as have a positive impact on joint development and bone strength. There are some excellent guides, such as that from the Muscular Dystrophy Campaign¹, around equipment choices for helping manage these conditions.

Postural support

Postural support devices for children affected by neuromuscular disorders have developed historically for stabilizing muscle tone, preventing spinal deformity, and enabling functional movements, and can involve specialist seating systems that are highly adaptive mechanical systems that provide full body support with a series of lateral supports – for example see Figure 1.

These systems ensure the occupant is held in a 'neutral' posture, and may require adjustment by a specialist as the



Figure 1. The Chunc Octoback – a multi-adjustable seating support system

occupant's needs change, which can be many times a year. Nevertheless, this follow-up ordinarily only looks at the occupant's needs during the short period they are in the clinic.

Though necessary for the bigger picture, this 'static' seating approach does not allow for the needs of the occupant as they change through the day, with changing levels of fatigue, and changing activities.

Dynamic support

What is needed is to add some dynamic seating elements (both passive and active examples are covered in some detail in another article²). Dynamic postural management seating systems are designed to move with the occupant while maintaining the occupant's contact with the support surfaces.

For wheelchair occupants who extend or move frequently due to high muscle tone, these types of solutions are clinically proven to protect them from injury and reduce damage to the seating system³.

In addition, movement in the system also helps to train functional movements and provide sensory input³, which is critical to the development, independence, and quality of life of a child.

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Alongside the dynamic options built into the wheelchair frame, the powered dynamic options which might be of value to an occupant could be tilt or recline, and adjustable leg supports. Taking this further would be powered sit to stand, depending on the progressive state of the disorder. These are gross adjustments.

Finer control can be offered by dynamic postural support devices, such as chest or shoulder harnesses, with the shoulder straps created from stretch materials which help the occupant regain their original posture after moving out of it for functional purposes.

Dynamic postural management

Further finer dynamic postural management can best be achieved by an active dynamic system within the seating system, which will allow for localised active postural management, and adjustment, as the day progresses, and the occupant's needs change.

Over the years, manufacturers have come up with some novel approaches, such as alternating pressure packages akin to those used in alternating pressure mattresses, but these have been aimed at protecting skin tissues by relieving pressure from alternating areas. However, users have found that these systems do not help their positioning needs.



Figure 2. The Aergo PS seating system

In contrast, a system with individually controlled air-filled bladders in the lumbar, thoracic lateral, thigh, and left and right pelvic support regions of a seating system is providing the means to manage the occupant's changing seating needs during the day – this is encapsulated in the Aergo PS seating system (Figure 2).

Summary

Most prescribed seating systems are static, and meet only the basic positioning needs at the time of set up. Many wheelchair clients, however, need minor changes to help achieve different functional goals, and for those with neuromuscular disorders in particular, to offset the consequences of fatigue affecting their motor functions over the day. The provision of both passive and active dynamic systems will be of benefit to both children and adults, particularly those with progressive disorders.

References

1. Muscular Dystrophy Campaign (2011) *Wheelchair Provision for Children and Adults with Muscular Dystrophy and other Neuromuscular Conditions: Best Practice Guidelines*
2. ter Haar MB (2022) *Let's Get It Clear: Dynamic Seating – What does it involve? THIIS*
3. Lange ML et al (2020) *RESNA Position on the Application of Dynamic Seating*



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