

# Complex posture management: A person-centred care approach for an individual with hip flexion limitations and considerations for wheelchair seating

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# Presenting condition:

- Why: "I don't want a moulded seat" Pain, seat adjustment limitations
- Who: Motivational speaker, 24-hr care, disability rights advocate
- Current seating system: does not accommodate hip flexion limitation
- Posture and secondary complications: oxygen desaturation from 97% to 84% with more neutral alignment in trunk
- Left side: impingement of rib cage over left iliac crest; pressure on lateral trunk support; hip flexion limitation driving pelvic obliquity
- Right side: severe pelvic obliquity with weight through greater trochanter;
- Diagnosis: Merosin deficient congenital Muscular Dystrophy (MDC1A)

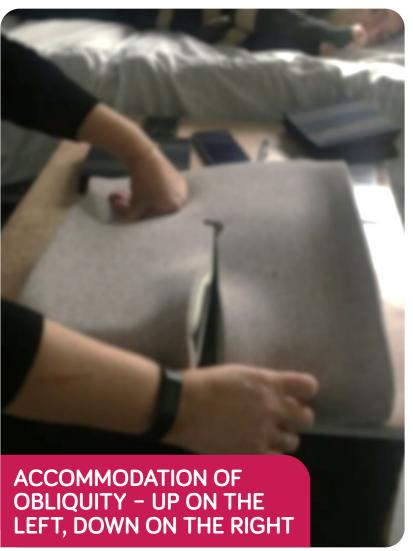
# Challenges:

- 24/7 posture management = Improve comfort, function and reduce secondary complications
- Hip flexion limitation can exacerbate obliquity and trunk asymmetry<sup>1</sup>
- High-risk of pressure injury with indications for support in lying and sitting<sup>2</sup>
- Pain for client on travel; home visit required
- Spex Flex<sup>3</sup> trial successful, but no adjustment for current wheelchair backrest to be raised to accommodate new seat height = further assessment required
- Private Therapist enters prize-draw for Flex cushion = win for the client (?)
- Client goals + knowledge/confidence/skill of full team = managing expectations<sup>4</sup>
- COVID-19 pandemic $^{5,6,7}$  and reallocation of resources = ? Person-centred care<sup>8</sup>
- Geographical challenges and logistics

### Stage 1: Spex Flex assessment and trial







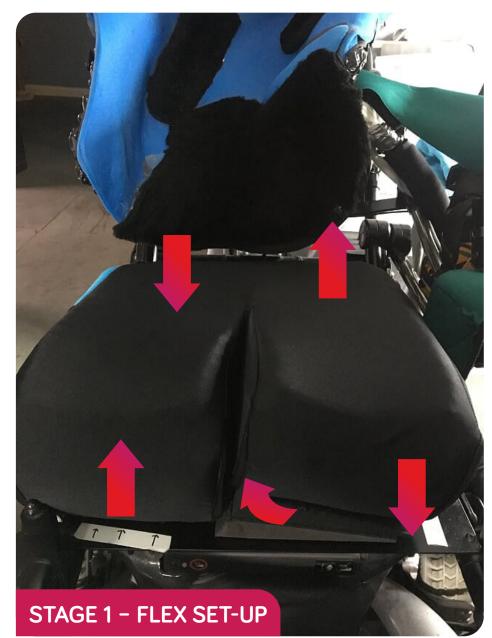
1. Spex Flex trial successful but ongoing challenges

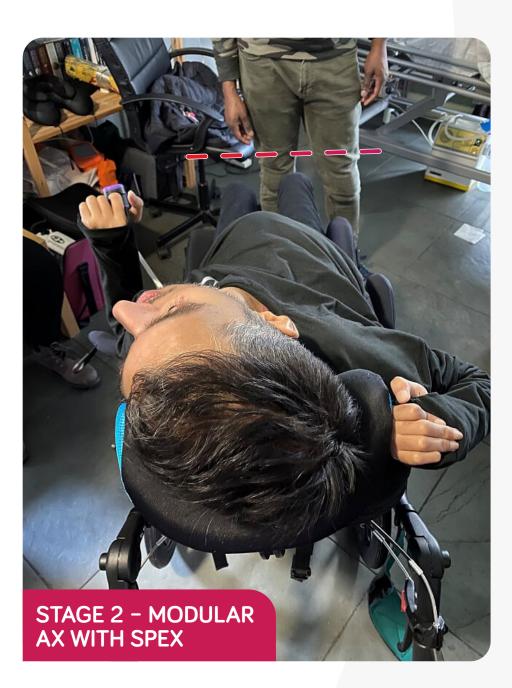
2. Spex seating
system trial
successful (postural
support / breathing)

3. Full MDT buy-in, but order & handover pending due to COVID-19 ON HOLD:
- 24/7 PCM\*

- Goal achievement







## Person-centred goals<sup>9</sup>:

- To be able to sit for 30 minutes without requiring repositioning from my care team
- Pain no more than 8/10 (intense) when in the wheelchair if pain in lying is around 6/10
- Not to have to rely on cushions/towels/add-ins for comfort and head support
- To sit in the wheelchair for up to 6 hours, three times a week
- To attend the UK Design conference in 2021 for up to three days
- Fully adjustable and configurable seating system that can change with the client's needs

### Solutions & Outcomes:

Achieved: Joined up working (Private/NHS/Mobility Supplier/Spex Ltd)

- Spex full system: Supershape back support, axial lateral hip supports, Flex cushion, axial lateral trunk supports, zoom extended comfi headrest, extension brackets for offsetting backrest shell to reinforce support and offer improved stability and comfort reconfigurable to meet ongoing postural changes
- Head supported, seat and back comfort & contact, configurable seating system, O<sub>2</sub> saturation maintained on assessment, hip flexion limitation accommodated

### Ongoing:

- Temporary halt to the seating system process and 24/7 posture management due to COVID-19 pandemic–access/coordination/delivery to high-risk individuals seating configuration easily adjustable when services recommenced
- 6 monthly posture and seating reviews and seating configuration adjustment to meet his changing needs.
- From mid-2021 pain reduced to 5/10 when in the wheelchair- cushion is like a 'cloud', Spex supershape back support like a 'hug'
- UK Design conference 2021 cancelled, but instead presented a live TEDx talk (13 hours sitting) and now resumed longer community-based social events.
- Pain free sitting tolerance increased from 10 minutes to 1h30 with use of Flex cushion right thigh external rotation

### Considerations:

- Pelvis is always the foundation for seating and affects upper and lower body<sup>2</sup>
- Posture management should not be at the expense of comfort or function
- What total support system<sup>10</sup> is best suited to allow for the flexibility and inherent adjustability required for complex postures and progressive conditions?
- Wheelchair interface = person + seating + base/chassis

Rehab Managment. https://www.rehabpub.com/conditions/neurological/cerebral-palsy/24-hour-posture-care-management-supporting-people-night-day/

- All seating components need to be configurable and relate to one another.
- How do we evaluate outcomes and offer person-centred care amidst the COVID-19 pandemic?
- Wheelchair seating is only one component of 24/7 posture management<sup>2,11</sup>

### We'll be here at:

References:

(1) Ágústsson, A., Sveinsson, P., & Rodby-Bousquet, E. (2017). The effect of asymmetrical limited hip flexion on seating posture, scoliosis and windswept hip distortion. Research in Developmental Disabilities, 71, 18–23. (2) Pope, P. (2007). Severe and Complex Neurological Disability. Elsevier. https://doi.org/10.1016/B978-0-7506-8825-3.X5001-5; (3) Spex Flex Cushion. (2019, April 29). Spex Seating. https://www.spexseating.com/products/cushions/spex-flex-cushion; (4) Tudor, L. E., Keemar, K., Tudor, K., Valentine, J., & Worrall, M. (2004). The Person-Centred Approach: A Contemporary Introduction. Macmillan International Higher Education. (5) Coronavirus: How to help safely, (2020. March 26). GOV.UK. https://www.gov.uk/government/publications/coronavirus-how-to-help-safely; (6) COVID-19: Guidance on shielding and protecting people defined on medical grounds as extremely vulnerable. (2020, March 21). GOV.UK. https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19; (7) Staying at home and away from others (social distancing). (2020, March 23). GOV.UK. https://www.gov.uk/government/publications/full-guidance-on-staying-at-home-and-away-from-others; (8) Raut, G. (2017, May 5). What person-centred care means | First Steps [Text]. RCN. https://rcni.com/hosted-content/rcn/first-steps/what-person-centred-care-means; (9) Zaza, C., Stolee, P., & Prkachin, K. (1999). The Application of Goal Attainment Scaling in Chronic Pain Settings. Journal of Pain and Symptom Management, 17(1), 55–64. https://doi.org/10.1016/S0885-3924(98)00106-7; (10) Lange, M., & Minkel, J. (2018). Seating and Wheeled Mobility: A Clinical Resource Guide. Slack Incorporated. (11) Kittelson-Aldred, T., & Hoffman, L. A. (2017, September 8). 24-Hour Posture Care Management: Supporting People Night and Day.