



A life-long perspective on sitting - from child to adult with a neuromuscular disease

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Background

Preventive measures are key to ensuring good sitting postures in people with neuromuscular diseases (NMD) who have been wheelchair-users since childhood.

Today, children with severe NMD survive childhood and many live long into adulthood.

We see adults who have developed postures during childhood that we want to prevent other children from developing.

The most common tools for sitting analysis only offer here-and-now analyses and do not account for disease progression.

This poster uses spinal muscular atrophy type 2 (SMA 2) as an example.

Aim

With preventive measures we want to

- ensure the best possible functional capacity and minimize scoliosis.
- preserve the best possible sitting posture throughout life.

Conclusion

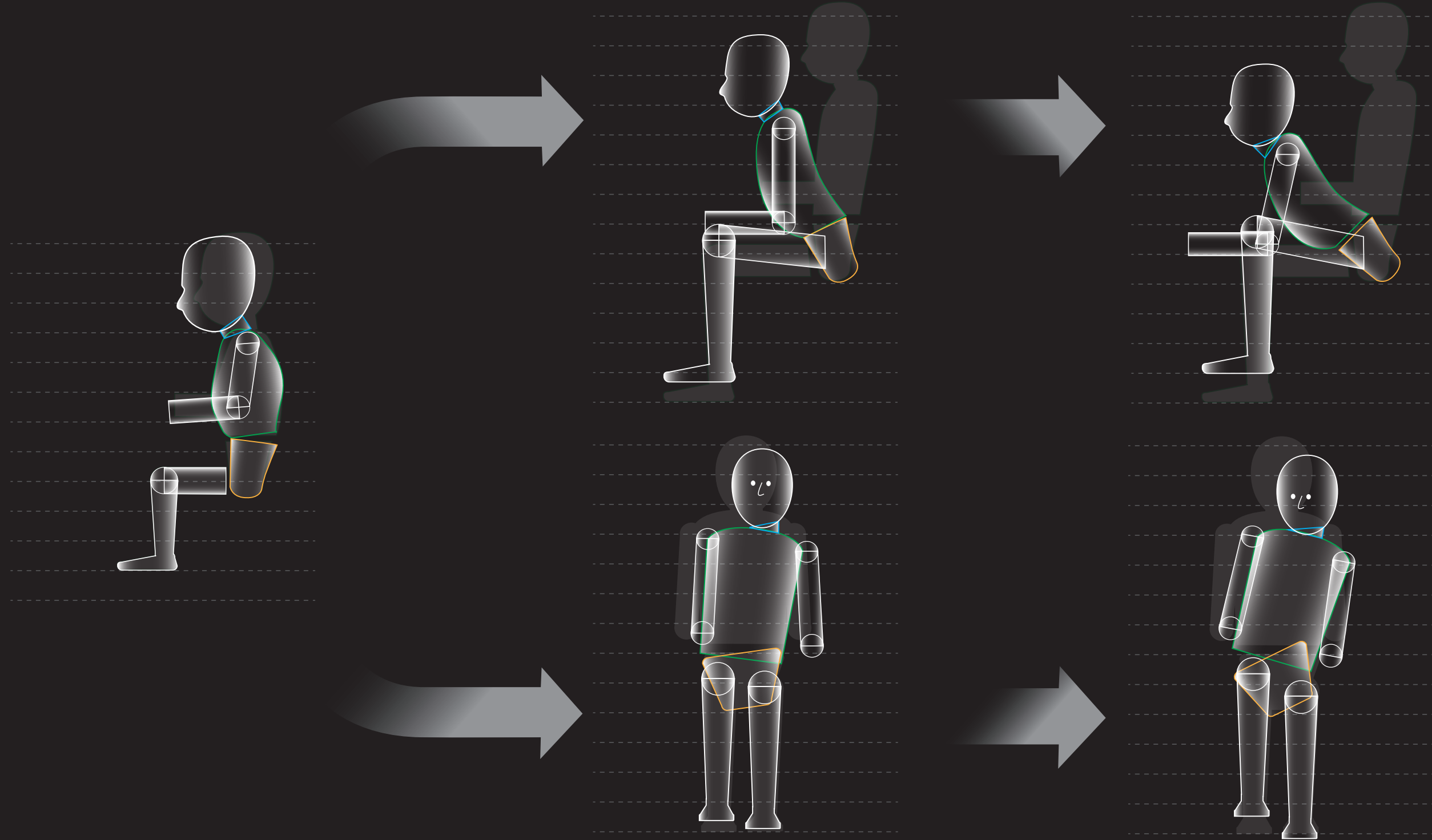
Sitting postures established during childhood are difficult to change in adulthood. Adjustments of the sitting posture in children should aim to ensure adequate sitting posture as an adult.

Already when the child begins to form its first movement patterns, i.e. when the child gets its first wheelchair, asymmetries should be prevented.

Knowledge about the disease and expected movement patterns during life is key to making adjustments of the wheelchair that point towards adulthood.

Adjustments require ongoing preventive measures as the child grows and/or loses muscle strength.

Development of sitting patterns from child to adult without corrective interventions



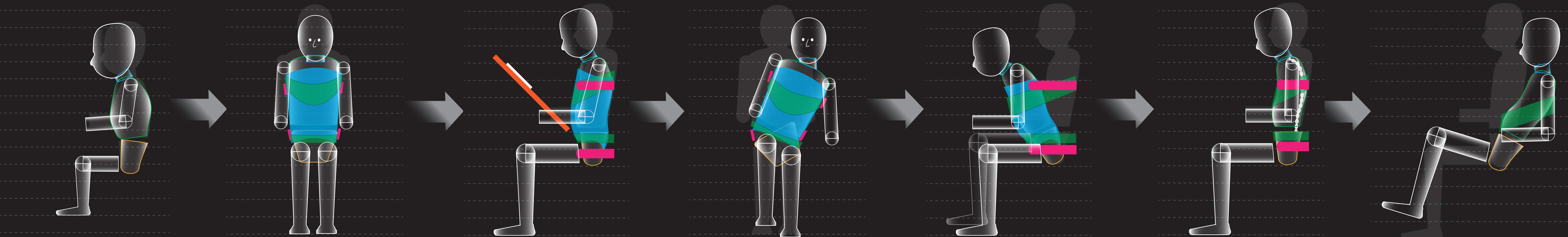
The child will always adjust its body so that its head is stable, eyes are horizontal, and arms and hands have the best possible function.

As the child loses muscle strength, the need for stability increases. The child achieves this by tilting the pelvis forward and/or to one of the sides, resulting in increased asymmetry.

Over the years, asymmetry and collapse of the torso will result in contractures, and the person will be unable to stretch out.

Later in adulthood, the person will experience pain in the pelvic region, shoulders and neck, as well as various forms of in- and outside pressure. Contractures impede functionality and makes personal hygiene difficult. Rotation of the neck impairs forward vision and makes tracheostomy difficult.

Development of sitting patterns from child to adult with corrective interventions



Early in childhood, the body collapses in a long kyphosis of the back and lordosis of the neck. The pelvis is tilted backwards. A brace can stabilize the natural curves of the back.

The first wheelchair should be adapted with symmetric inserts for body support, hip belt, chest belt and concave neck support.

The child sits as close as possible to the edge of the table with adjustable tabletop to preserve upright posture.

Continuous correction to symmetric posture. The child will experience a brief loss of functionality. Risk periods: growth spurts, sickness and puberty.

Muscle strength does not increase as the child grows, and more asymmetries develop.

Spine surgery is necessary when scoliosis is so severe, that body can no longer be supported in an upright posture.

Immediately after spine surgery, the seat should be adjusted to fit the new posture and corrected to ensure symmetry.

Later in adult life, the body needs to be tilted backwards for relief and to ensure stability of the head and body.

Body support
Belts
Brace

Key points

- Stabilization of the pelvis in neutral position with hip belt or adjustable chest belt
- Positioning supports fitting tightly to the body. Must be adjusted without outerwear
- Stabilization of the head in symmetric position
- Upper arms are vertical, armrests are close to the body and should move in parallel with the seat
- Light-weight joystick in non-dominant hand (shortened joystick spring)

Challenges

Patients do not always feel that their posture is wrong and are not motivated for changes.

Guidance of both patient, parents, relatives, and other caregivers is key to promoting the purpose.

As the sitting posture is corrected, the need for other adaptations will occur, e.g. placement of the computer, table height, methods of transferring, etc.