A SMALL GUIDE TO IMPROVE SEATING IN PERSONS WITH DUCHENNE MUSCULAR DYSTROPHY

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Introduction

An understanding of the disease and disease course is necessary to understand the problems one can encounter while being seated and the possible solutions for this.

Duchenne Muscular Dystrophy (DMD) is an X-linked recessive disease affecting both striated and smooth muscle tissue, as well as the brain. The disease becomes noticeable through an inability to run, get up from the floor and weakness in the neck muscles. It progresses with loss of leg strength leading to inability to walk and to stand. In the next phase, arm and back muscles develop increasing weakness leading to loss of ability to lift the arms and instability in the trunk. The head balances on the trunk, and when the trunk starts to deform due to weakness, positioning the head is also impacted.

Due to loss of muscle tissue and fibrosis contractures appear. These contractures also impact positioning while seated. It is of importance to prevent or delay the formation of contractures as much as possible. Inadequate seating has a negative impact on scoliosis as well as on cardiac and pulmonary function which must be prevented. In addition, bad seating can cause pain and discomfort.

A stable and balanced seating position means positioning a chain of joints in the optimal way: ankles, knees, hips, pelvis, spine, arms and head.

The aim of good seating is comfort, preventing pain while seated with optimal seating balance, and the ability to perform tasks with the hands.

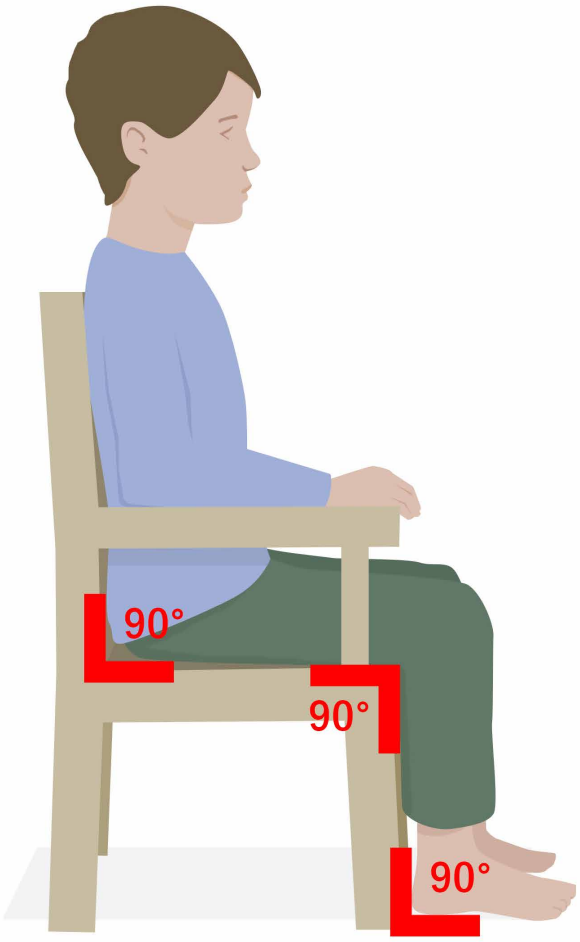
Ambulatory phase

Children with DMD already have problems getting up from a low position such as the floor or a low chair in the early ambulatory phase. It is important to provide them with seating support when sitting for a longer period such as in school. A height-adjustable chair (to allow for growth), which allows a child to place their feet at a 90 degree position at the ankle and knee and put their arm on an armrest. This helps the child to get used to a well-balanced and stable position. The armrests help the child to stand.

In the late ambulatory phase, when a child with DMD often walks on tiptoe due to weakness in the pelvic muscles and fibrosis in the calf muscles, it is important to delay the development of contracture in the ankle by positioning the child as described above. Many children tend to maintain a tiptoe position. Parents and teachers must be watchful and correct this position. The tiptoe position is unstable and can cause pain in the back or around the pelvis. It can also cause asymmetric contractures around the hips and thus a pelvic tilt. The latter has a negative impact on the position of the spine and head.

Figure of seating position ambulatory phase:

Note the 90 degree ankles in both legs and the elbows in static position.



Possible solutions

1. Seating in a 90 degree position in the legs and arms (be aware of the height of the armrest: the shoulders should be in neutral position).

2. If the child sits in a wheelchair, the knees are either in a 90 degree position or at a slightly higher angle. The ankles should still be in 90 degree position on the footrests.

3. Use of ankle-foot-orthoses during the night to delay contracture formation.

4. Do stretching exercises for the legs and back to delay contracture formation.

5. Do not use stiff shoes reaching above the ankle in this phase as gait is mainly on tiptoe to maintain balance; shoes should have flexible soles to allow this type of walking.

6. If the child is in a wheelchair, use a pelvic seat belt.

THE AIM OF GOOD SEATING IS COMFORT, PREVENTING PAIN WHILE SEATED WITH OPTIMAL SEATING BALANCE, AND THE ABILITY TO PERFORM TASKS WITH THE HANDS.

Early non-ambulatory phase

In the early non-ambulatory phase, the child with DMD has an active seating position, can correct his own seating position and can reach forward and lift the arms from the armrests. This will become more difficult when the child grows older and enters the transition period (late non-ambulatory phase). Thus, regularly assessing a child or youngster's remaining functional abilities is important for the seating position and the adjustments that have to be made for a stable and balanced seating position.

In the early non-ambulatory phase, positioning the child in the wheelchair is the same as in the ambulatory phase: feet on the foot rests, ankles, knees and hips at 90 degree. It is important that the wheelchair cushion allows and supports this position, and can distribute the pressure of the trunk to the pelvis. If a child tends to take a tiptoe position, the weight of the trunk is displaced to the sit bones of the pelvis (ischial bone). This can cause discomfort and pain. The thighs help to support the trunk weight and thus only part of the weight is placed on the sit bone.

In this phase, active positioning helps the child to move their arms forward. If the chair or the pelvis are slightly tilted backwards, it is more difficult to reach forward. An upright position also helps the child to propel/ rock the wheelchair by himself using the hand rims.

If the child or adolescent tends to maintain a tiptoe position on the foot rests or lets their feet hang over, both unstable positions for seating, there is a risk that the knees fall outwards, the so-called open book position. This can also appear at a later stage of the early non-ambulatory phase due to weakness of and contractures in the pelvic muscles. The open book position can be asymmetric, which may lead to a lateral pelvic tilt or pelvic rotation, meaning that the upper rim of the pelvis is higher on one side than the other or the pelvis points forward on one side compared to the other.

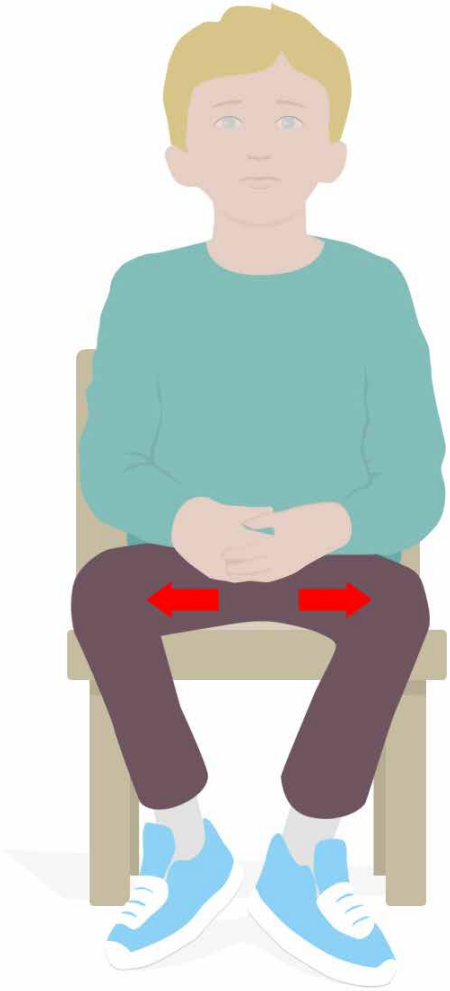
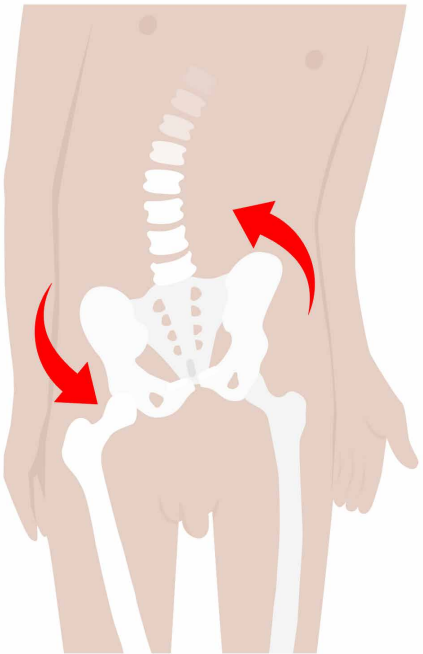


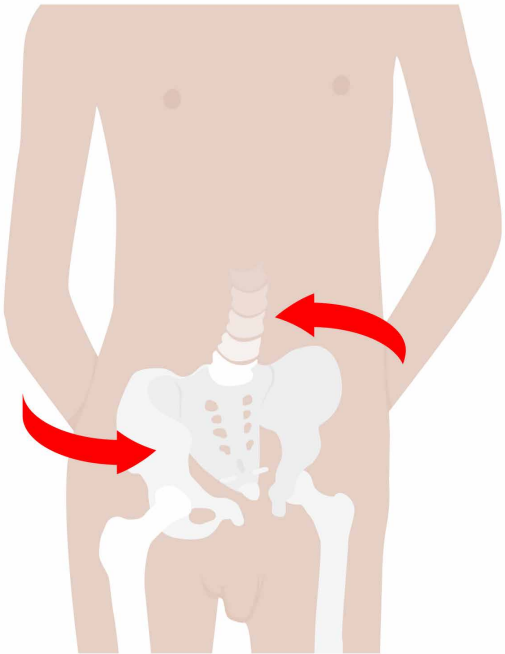
Figure of open book position

The knees are falling to both sides with as consequence the feet are turning with the soles to the inside.

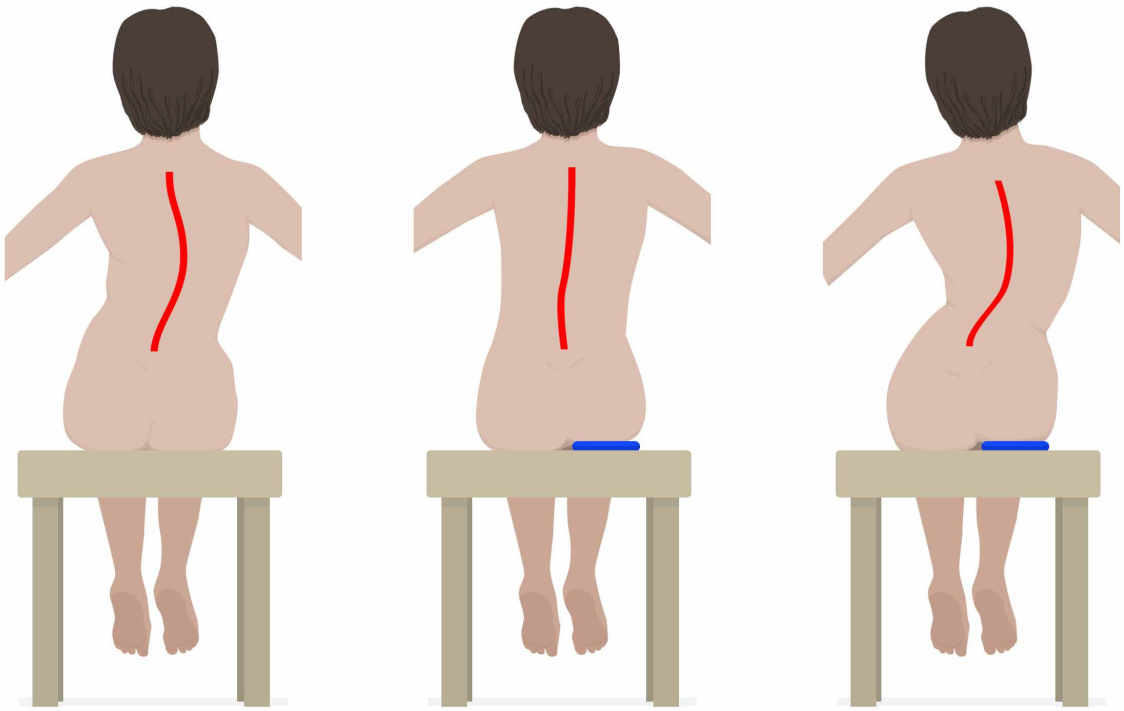
Figures of lateral pelvic tilt (below left) and of pelvic rotation (below right)

Lateral pelvic tilt or pelvic rotation can be present on either of the sides or it is also possible that both pelvic tilt and pelvic rotation can be combined.





Some children/youngsters develop scoliosis due to weakness of the back muscles. The vertebral column is normally straight when seen from the front or the back, but in case of a scoliosis a developing curve or curves can be seen, the so-called C-type or S-type scoliosis. A good resting position of the arms on the armrests helps to stabilize the back. Also be aware of a wheelchair that is too wide so the child/youngster can slip down in the chair, which causes asymmetrical posture due to 'hanging to one side')



Figures examination of a possible scoliosis and whether a scoliosis is correctable (middle) or not (right): sitting on a bench without arm or feet support

Possible solutions:

1. Seating in a 90 degree position in the legs and the arms. (be aware of the height of the armrest: the shoulders should be in neutral position).

2. If the child/youngster sits in a wheelchair, the knees are either in a 90 degree position or at a slightly higher angle. The ankles should still be in 90 degree position on the footrests.

3. Use shoes atl ankle height and with shoe laces to position the feet on the footrests and stabilize the ankles.

4. Use supports on the wheelchair that prevent an open book position.

5. If the width of the wheelchair is not adaptable, use foam to adapt to the child's posture, particularly around the pelvic area.

6. Be aware of the arm position if you must adapt the width of the wheelchair. The arms should not be positioned in an outward angle in the shoulder, they should be close to the trunk.

7. If there is a pelvic tilt, first examine whether this is structural or not. If it is still correctable, adapt the cushion by pushing the lower half of the pelvis upwards to achieve horizontal alignment of the pelvic rims. If it is structural, accept the tilt and make the cushion lower on that side. Always look what the trunk is doing while you try out the adaptations. The trunk should be positioned correctly in the middle of the pelvis.

8. If there is scoliosis, first examine whether it is balanced: the head is in the middle of the pelvis (if the pelvis is aligned as described in 7). If the scoliosis is unbalanced, provide the wheelchair with side supports: assess how much support is needed, but be aware of the armpit. There should be no pressures on the armpit and the child must be able to move his arms normally.

9. Use a pelvic seat belt; if the scoliosis is unbalanced, use of a 4-point harness is recommended.

Late non-ambulatory phase

If the youngster has increasing problems to correct his/her own posture, a stable position is essential to enable him to perform activities with the arms and hands. More support is needed for the back and a balanced position of the trunk. It is essential that the youngster is still able to see his hands, while performing activities at the table or on the removable table or tray of the wheelchair.

A stable position is also essential for driving an electric wheelchair outdoors, as bumps and uneven surfaces can disturb the seating position or unwillingly displace arms and hands. As far as positioning of the arms/hands are concerned, a symmetrical support helps to lesson displacement. Particularly, if the youngster uses an arm support like exoskeletons this may lead to asymmetrical support while driving a wheelchair.

If the neck muscles also grow weaker, the position of the head needs attention both while standing or driving a wheelchair. Adjustments may be necessary during the day as the youngster becomes fatigued.

Possible solutions:

1. Seating in a 90 degree position in the legs and the arms (be aware of the height of the armrest: the shoulders should be in neutral position).

2. If the youngster/adult sits in a wheelchair, the knees are either in a 90 degree position or at a slightly higher angle. The ankles still should be in 90 degree position on the footrests.

3. Use shoes that come tol ankle height and with shoe laces to position the feet on the footrests and stabilize the ankles.

4. Use supports on the wheelchair that prevent an open book position.

5. If the width of the wheelchair is not adaptable, use foam to adapt to the child's posture, particularly around the pelvic area.

6. Be aware of arm positioning if you have to adapt the width of the wheelchair. The arms should not be positioned at an outward angle in the shoulder, they should be close to the trunk.

7. If there is a pelvic tilt, first examine whether this structural or not. If it still correctable, adapt the cushion by pushing the lower half of the pelvis upward to achieve horizontal alignment of the pelvic rims. If it is structural, accept the tilt in the cushion and make the cushion lower on that side. Always look what the trunk is doing while you try out the adaptations. The trunk should be positioned correctly in the middle of the pelvis.

8. If there is scoliosis, first examine whether it is balanced: the head is in the middle of the pelvis (if the pelvis is aligned as described in 7). If the scoliosis is unbalanced, provide side supports: assess how high support is needed but be aware of the armpit. There should be no pressure on the armpit and the child/youngster must be able to move his arms normally.

9. If the trunk muscles are too weak, side supports become necessary: assess how much support is needed but be aware of the armpit. There should be no pressure on the armpit and the child/youngster must be able to move his arms normally.

10. For weak neck muscles, a support is needed to stabilize the back of the head that is slightly curved around each side of the head, but be aware that the adult is still able to look to each side. If the head tends to deviate to one side, extra support is required. This can be attached to the neck support.

11. Be aware of the positioning of the arms on the wheelchair. the adult must still be able to use the joystick and his gaming or environment control. The size of the bulb/ball of the joystick can be very important either for steering the wheelchair or for stable positioning of the hand.

12. Use a pelvic seat belt; if there is an unbalanced scoliosis, the use of a 4 point belt is recommended.

Acknowledgement:
I would like to thank all the patients that have given me the confidence to treat them including seating and have learned me through the years what is important in seating. Also many thanks to the occupational therapists and physical therapists with whom I worked and have enlarged my knowledge on seating through fruitful discussions.

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About the World Duchenne Organization
The World Duchenne Organization is an umbrella organization of national patient organizations for DMD and Becker MD (BMD) around the world. This organization aims to inform parents and people with DMD/BMD based on latest research, promote good standards of care, and actively participate in efforts develop safe and effective treatments for DMD/BMD and find a cure.

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