

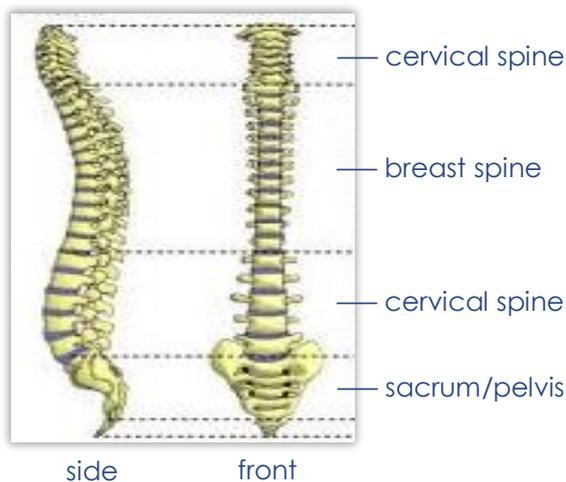
Scoliosis in Rett syndrome

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Scoliosis is a deformation of the spine in rotation and lateral bending to flexion and lateral-flexion. Shoulder and pelvis are included and in a wrong position (too high and too much rotated).

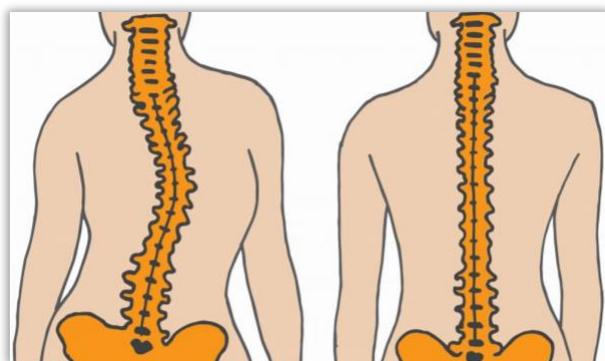
Normal anatomy



Usually the spine has a straight position from the pelvis/sacrum, the lumbar spine, the breast spine to the cervical spine.

The spinal curvatures are at sacrum and at the breast spine backwards, lumbar spine and cervical spine are ventral.

Pathological anatomy



Scoliosis:

- The legs seem to have a leg length difference
- The pelvis at one side is rotated forward and higher than the other side
- On the one side you can feel the ribs – this is called rib hump
- The shoulder at one side rotates forward and has a higher position than the other shoulder

Causes for Scoliosis/Rett syndrome

Reasons for scoliosis are muscle diseases, accidents, or congenital malformation of the vertebra. Mostly (in 90%) the reason is unknown – therefore it is called “idiopathic scoliosis”.

False posture often causes a weakness of the spine. Children with Rett syndrome have their own opportunity to move or place their body. Their monotonous behavior like rubbing or tapping hands causes evasive movements in the shoulders and at the pelvis. For these children there might be a combination of idiopathic scoliosis and monotone physical activities.

The monotone activities may also show the Rett person's emotional situation. It is not possible to stop these activities. But you can try to ease the posture and the weight of the arms and the legs.

Based on the monotone hand-situation, the position of the arms and the spine is always the same. The arms have their own weight and there is not enough variety for the body, especially for the spine. The hand-gesture has a lot of influence on the elbow, shoulder, and spine. These parts adjust to permanent load and cause problems.

As the reference person you will be able to manipulate the spine early.

At this point you may focus on one or more of the following:

- Walking and standing
- Sitting in a wheelchair or somewhere else
- Lying

In all cases you have to find a balance and variety for everyday life.

Walking and standing

Walking

- Different ways to walk
 - she has to lift her legs more or less
 - walk on a soft ground
 - turn around
 - one leg is in a higher position than the other
 - faster or slower
 - go sideways mainly to the side where the pelvis is lower
 - different shoes on the left and right leg
- The arm (also the elbow) where the shoulder is lower should lay on the shoulder of the reference person during walking – this person also makes contact with the rib hump and put soft pressure on it
- Be careful with compensating the leg length difference – the problem is often placed at the pelvis!!

Standing

- The arm where the shoulder is lower than the other has to reach further up; e. g. to put on or get something from an over-head hanging shelf
- The legs stand on different high levels, e. g. a small step

Sitting in a wheelchair or somewhere else

Be careful with very soft seat cushions – the body would not be corrected in a sufficient way

- The knees should be lower than the buttock to have a correct position for the lumbar spine (ventral position)
- Where the pelvis is **lower**, this part of the buttock gets an underlay (only a few centimeters) so that the higher part of the pelvis comes back to the seat and the spine will be in the corrected position; it would be helpful if there is a particular spot/seat for the girl (or boy) to use (by eating, playing) and of course in the wheelchair
- The leg where the pelvis is further back should be moved forward as far as possible (eg. put a pillow behind the pelvis)

- The lumbar spine needs a back support to push it forward
- The arm where the shoulder is lower should be placed higher (at the height of the shoulder)

Lying

It is possible to correct the girls position for a longer period if there is enough observation and a following correction.

Supine position

- Pelvis: where it is further to the back there should be a small pillow (eg. within the clothing)
- Shoulder: the arm where the shoulder is closer to the pelvis should be placed above the head

Abdominal position

- Pelvis: the pelvis which is further to the front gets a small pillow
- Shoulder: the arm where the shoulder is closer to the pelvis should be placed above the head

Lateral position

- The side where the rib hump is, should be on top; eg. if the rib hump is on the left side you have to take the right lateral position
- It would be great if she could support her body with the lower arm

If you have the possibility to support every day than your child has the chance to form a habit in the daily life.