



RETT SYNDROME ASSOCIATION UK

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Physiotherapy Input for children/adults with Rett Syndrome

When a person is diagnosed with Rett syndrome, it is most important that s/he is referred for physiotherapy. As a baby, the child with Rett syndrome will have full range of movement in all her/his joints and every effort must be made to maintain this range and delay/prevent the onset of deformities. There is a very high incidence of spinal deformities, either kyphosis or scoliosis or both and it is advisable to refer to an orthopaedic consultant before the onset of spinal problems, for a baseline to be taken. Standing and walking involve extension of the knees, hips, and spine, and will therefore help to delay the onset of spinal deformities. Correct seating with postural management is most important from an early age. It is possible to detect a stiffness in side flexion of the spine before the actual onset of a scoliosis and physiotherapy input should aim to increase/maintain spinal mobility. Hydrotherapy and riding are often helpful.

Some young people with Rett syndrome have low muscle tone and physiotherapists can advise on correct positioning to minimise deformities. It may be difficult to envisage onset of deformity when a child is floppy with extremely mobile joints, but it should be noted that a floppy child could develop tight Achilles tendons (heel cords) whilst remaining floppy elsewhere. Tight Tendo-achilles would interfere with that child's chances of standing and walking. In cases of extremely low muscle tone, there is an increased risk of anterior dislocation of the hips and careful positioning is required, especially during sleep.

Many of the older people have problems with subluxation or dislocation of one or both hips. Spinal deformities can lead to pelvic obliquity which in turn leads to windsweeping of the hips and the adducted hip may be at risk of dislocating. It is most important to prevent muscle contractures, maintain the ability to weight bear, and to walk. It is helpful to request hip X-rays when the spine is being monitored.

Increasing muscle stiffness is common as the people with Rett syndrome get older. Relaxation and passive movements are necessary to combat fixed deformity and every encouragement should be given for active movements. Again hydrotherapy is helpful. Increased vigilance is required to maintain the ability to weight bear/walk. Two people may be needed to assist with walking - one on each side.

Physiotherapy input sometimes decreases as the girl gets older whereas the **need** for physiotherapy increases as the girl gets older, heavier and stiffer. "Use it or you lose it"!

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