

POSITIVE STEPS

Rett Syndrome

Rett syndrome is a rare genetic disorder affecting brain development that results in physical and mental disability.



The main early sign for Rett syndrome is repetitive hand movements and beginning to lose previously gained skills, or miss developmental milestones.

It can present in a variety of ways ranging from mild to severe.

Rett syndrome can be recognised in children as early as 6-18 months.

It is caused by a gene mutation and how it presents depends on the location, type and severity of this mutation in the chromosome.

Children diagnosed with Rett syndrome can live long and happy lives into middle age and beyond!

Important Information

Rett syndrome affects approx. 1 in 12,000 girls born each year and is rarely seen in boys.

Common coinciding conditions include; gastrointestinal problems, scoliosis, epilepsy, unusual breathing patterns, sleep changes and low bone density

Symptoms and What to expect



STAGE 1

Early Signs

Normal development to 6 months old with some subtle symptoms such as low muscle tone or developmental delay

Regression

This stage begins between 1 and 4 years old. Significant deterioration in skills such as communication, memory and mobility. Often similar symptoms to autism

STAGE 2

Plateau

Between 2-10 years, children enter this stage. Many children remain in this stage for the rest of their lives. There may be some improvements in behaviour and mobility

STAGE 3

Deterioration in Movement

This can last for a long period of time, people often experiences a greater spinal curve, weakness and muscle tone changes and loss of independence

STAGE 4

How Physiotherapy can help

Physiotherapy is important for people with retts syndrome as it aims to maximise and maintain the persons function and independence as much as possible

Exercises to facilitate improved posture management

Managing changes in muscle tone

Improving mobility

Stimulating hand skills and fine movement

Exercises to improve and maintain balance and coordination

Improve body awareness known as proprioception

Increasing cardiovascular fitness tolerance



Useful Resources

<https://www.nhs.uk/conditions/rett-syndrome/>

<https://www.rettsyndrome.org/>