Super Duper® Publications

Handy Handouts®

#192

Free informational handouts for educators, parents, and students

Rett Syndrome

By Kevin Stuckey, M.Ed., CCC-SLP

Rett syndrome (RTT) is a rare disorder characterized by normal early developmental growth followed by changes in typical patterns of mental and physical development. It affects several races and ethnic groups around the world.

Is Rett Syndrome like Autism?

Although symptoms are similar to those of autism, RTT affects girls almost exclusively, whereas autism affects boys at a rate of 4:1. Symptoms in RTT do not improve over time; they remain the same or worsen.

What are some signs and symptoms of Rett Syndrome?

Initial signs and symptoms of RTT begin with a slowing of head growth and/or a loss of muscle tone. Around one to four years of age, a child with RTT may stop talking, lose social and language skills, and develop extreme social anxiety.

Other symptoms may include difficulty walking and seizures. Apraxia—the inability to perform motor functions—is a severely disabling feature of RTT. Apraxia can affect every body movement, including eye gaze and speech.

What are the four stages of RTT?

Early Onset Stage

Stage 1

Age: 6 months to 1½ years

Duration: Months

- Symptoms may include: less eye contact, loss of interest in toys, delays in sitting or crawling, hand wringing.

Rapid Destructive Stage

Stage 2

Age: 1 to 4 years

Duration: Weeks to Months

- Symptoms may include: hand wringing/washing/clapping/tapping, hands moving to mouth repeatedly, breathing difficulties

Note: Some autistic-like behaviors may be present such as loss of social interaction and communication, general irritability, and sleep irregularities. You may also notice that the child has difficulty initiating motor movements or walking, and/or that head growth is slowing.

Plateau Stage

Stage 3

Age: Preschool to Adulthood

Duration: Decades

- Symptoms may include: apraxia, motor problems, and seizures; may show improvement in behavior including less

Handy Handouts®
Free informational handouts for educators, parents, and students

(cont.)

irritability, crying, and autistic-like features; may show more interest in surroundings, increased alertness, attention span, and communication skills

Note: Many girls remain in this stage for most of their lives.

Late Motor Deterioration Stage

Stage 4

Age: 5 – 25+ years (when the ability to walk independently is lost or for those who don't walk or move from stages 2 to 4)

Duration: Up to decades

- Symptoms may include: reduced mobility – muscle weakness, rigidity (stiffness), spasticity (muscle tension), dystonia (increased muscle tone with abnormal posturing of extremity or trunk), and scoliosis (curvature of the spine); previous ability to walk is lost.

What Can I Do for My Child with Rett Syndrome?

Children with RTT are rarely able to live independently and need help for most activities of daily living. There are some treatments available that can help to improve the quality of life. They are:

- **Physical therapy** – improves mobility
- **Speech therapy** – improves language and social skills
- **Occupational therapy** – teaches daily activities such as bathing and dressing
- **Medicines** – help with breathing irregularities and motor difficulties, controlling seizures

Resources

International Rett Syndrome Foundation (2008). Rett syndrome FAQ. Retrieved December 22, 2008, from http://www.rettsyndrome.org/index.php?option=com_content&task=view&id=14&Itemid=375

National Institute of Neurological Disorders and Stroke (updated June 2008). Rett Syndrome Fact Sheet – National Institute of Neurological Disorders and Stroke. Accessed 6/5/2023 from https://www.ninds.nih.gov/health-information/disorders/rett-syndrome?search-term=rett