

Extract from <http://www.mychildwithoutlimits.org/understand/rett-syndrome/rett-syndrom-treatment/>

While Rett syndrome has no cure, research suggests that intervention begun soon after the diagnosis offers the greatest chance of producing a positive impact on skills in later years. The earlier treatment starts, the better the possibility for learning as well as managing other problems developed by individuals with Rett syndrome.

Medical Management

The various health issues of Rett syndrome call for various treatments. Common issues include:

- *Nutrition and swallowing: Nutritional and caloric intake must be monitored. Nutritional supplements may be prescribed if caloric intake is not adequate. If the child breathes in (aspirates) food or has difficulty chewing, then a feeding tube may be helpful. Liquid nutrients can be delivered directly to the stomach via the tube inserted through the nose (short term) or through the abdominal wall (longer term). Getting necessary nutrients and maintaining an adequate weight may result in enhanced attentiveness, improved social interactions, optimal growth and provide an adequate intake of fluids and high-fiber foods to avoid or relieve constipation. Maintaining intake of recommended daily allowance of calcium and vitamins is important for health. In particular bone health is important in girls with Rett syndrome given the prevalence of osteoporosis.*
- *Seizures: If seizures are suspected, an EEG may be obtained as well as a referral to a neurologist. Medications are prescribed to control seizure activity for many girls affected by Rett syndrome. Input from a neurologist is important since some children with Rett syndrome have seizures that are refractory to treatment. Also, some of the breathing abnormalities seen in Rett syndrome may be confused with seizure events.*
- *Muscle stiffness, breathing irregularities (while awake), heart arrhythmias, constipation, gastrointestinal reflux ("heart burn"), anxiety, difficulties with sleeping and severe agitation may occur in some children with Rett syndrome. If a child has these symptoms, they should be evaluated and may be treated with medication.*
- *Orthopedic management is important for optimizing gait/skeletal alignment and for management of contractures and scoliosis.*
- *Cardiac: Sudden death has been reported to occur more commonly in individuals with Rett syndrome than the general population. It is not completely clear what causes this. However, many individuals with Rett syndrome have been found to have an abnormality on their electrocardiogram called prolonged QT. Prolonged QT can suggest a predisposition to cardiac arrhythmia. It is important for individuals with Rett syndrome to be evaluated for prolonged QT and to avoid medications which are known to prolong the QT. The International Rett Syndrome Association (IRSA) recommends the first EKG should be performed by age 5 and, if normal, repeated every other year. Hearing and vision should be evaluated and monitored regularly.*

Putting Together a Care Team

There are a number of ways to help reduce the effects of Rett syndrome. Most treatments are supportive and aim at addressing specific symptoms of Rett syndrome rather than trying to take on the disorder as an entire entity. Generally speaking, the goal of these treatments is to hold back the decline in abilities, enhance or maintain movement, and support social contact and communication. Most families and physicians find that what works best is a complex, interdisciplinary approach that includes many diverse kinds of therapies. These therapies, which range from traditional approaches to new and experimental ones, may include:

- *Physical therapy to help improve or maintain mobility and balance, address diminished motor skills, maintain flexibility and strengthen muscles. PT is also directed toward preventing deformities, such as reducing joint contractures. Weight-bearing exercises are helpful for bone health. Maintaining good postural alignment and bracing may help to slow progression of scoliosis.*
- *Speech-language therapy to assist with communication developing skills including use of non-verbal forms of communication and other methods of augmentative communication (e.g. picture communication).*
- *Occupational therapy to define goals and interventions to optimize basic life skills such as dressing, chewing, drinking and brushing their teeth, as well as in self-directed activities such as play and recreational activities. Further, OT can give girls with Rett syndrome greater control over their involuntary movements and improve purposeful hand movements, while also preventing their hands from contracting.*
- *Alternative approaches such as hydrotherapy (therapy using water to strengthen muscles and help alleviate pain), massage therapy and hippotherapy (a treatment strategy that utilizes a horse's movement to provide sensory input).*

Other health care professionals are vital members of the health care team involved in the treatment of people with Rett syndrome. They include: orthopedic surgeons, gastroenterologists, pulmonologists, cardiologists, neurologists, developmental specialists, developmental pediatricians, special education providers and nurses.