



THRIVING
with RETT



OCCUPATIONAL THERAPY GUIDE

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*You treat a disease: You win, you lose. You treat a person,
I guarantee you win — no matter the outcome. - Patch Adams*

Treating the whole person is imperative to success and that is what we as Occupational Therapists do. When you take the time to really care for a person, you will always win.

My name is Brian Rusin and I am a registered and licensed Occupational Therapist. I have been granted the opportunity to treat individuals with Rett Syndrome within a school setting. Each individual is special in their own way. Similarly, the characteristics of Rett Syndrome present differently in the individuals' abilities, emotions, and interactions.

Occupational Therapy can have very positive effects on individuals with Rett Syndrome. Occupational Therapy services may include:

- / Improving upper extremity functioning / range of motion (ROM)
- / Strengthening, standing tolerance, endurance
- / Fine motor skills
- / Activities of daily living (ADLs) such as feeding and functional mobility
- / Tolerating sensory input
- / Vision
- / Positioning
- / Usage of splints
- / Modifying / adapting the environment

 Occupational Therapists provide families with the tools needed to support learning and engage appropriately with the world around them.

The most effective Occupational Therapists work collaboratively with the family, teachers, case workers, other therapists and everyone else on the team in order to establish an effective plan to improve participation, well-being, and independence. OTs provide families with the tools needed to support learning and engage appropriately with the world around them and educate these families on how to use these tools.

"Occupational Therapy may be helpful in improving several aspects of life of an individual with Rett Syndrome. It can help a child be more functional and comfortable on a daily basis" (*Occupational therapy for Rett Syndrome, 2021*).

A good practice for OTs working with someone with Rett Syndrome is to employ the "just right challenge," which is defined as just slightly above what a person is currently able to do. In other words, it's an activity they can do but it requires a bit of a stretch. This is important for progressing individuals further with their goals.

Very important to Occupational Therapy is the understanding that proximal stability creates distal mobility.



Very important to Occupational Therapy is the understanding that proximal stability creates distal mobility. This phrase applies to everyone, especially individuals with Rett. To have proper functioning and mobility distally (arms/legs), there has to be stability proximally (midline structures/core). This is achieved by having the individual in different and sometimes challenging positions that engage/strengthen the core. These positions can vary from being in a prone on elbows (on tummy) position to side sitting. These positions do not only improve the core, but also engage head control and other muscles of the body. Remember to always provide adequate rest breaks to avoid fatigue and loss of interest in the activity.

Occupational Therapy improves range of motion within the upper extremities as well as incorporating interventions to assist with lower extremities. Performing passive range of motion, gentle joint compressions, and massage, can improve overall upper extremity range of motion as needed for increased participation in activities throughout the day.

I provide families with a home exercise program, along with videos of what I do with their child in order to implement activities at home. It's very important that the child or adult be performing exercises every day. If I see an individual three times a week, that means the family needs to be engaging him/her the other four days. They should safely follow guidelines/activities set forth by the Occupational Therapist.

There are so many articles and websites that associate the words "declining" and "regression" with Rett Syndrome. While these are real aspects of the disorder in many cases, I'm confident that regular and appropriate

Occupational Therapy can have an extremely positive impact on slowing declines and regressions. I have had tremendous success from the clients I currently work with. Individuals with Rett have improved fine motor skills, range of motion, self-feeding, standing tolerance, endurance, and overall strength. Throughout my experiences and personal conversations, I associate the words PROGRESS and POSITIVITY with Rett. You cannot view the glass as half empty or even as half full, but as REFILLABLE. There is always a way to change the situation and the path ahead in order to achieve your goals and have positive outcomes.

Additional information:

For further information, the best way to contact and reach me is through email at: Brian.rusin@gmail.com

Feel free to check out these websites to gain more knowledge about the benefits of Occupational Therapy for Rett Syndrome:

<https://www.rett.ca/wp-content/uploads/2013/07/Occupational-and-Physical-Therapy-for-Children-and-Adults-with-RTT-Captain-Dermody.pdf>

<https://childdevelopment.com.au/areas-of-concern/diagnoses/rett-syndrome/>

<https://rettsyndromenews.com/rett-syndrome-and-exercise/>

References:

Occupational therapy for Rett Syndrome. (2021). Retrieved April 19, 2021, from <https://www.asdclinic.co.uk/conditions/rett-syndrome/occupational-therapy-for-rett-syndrome.php>

Subramaniam, V. (2019, April 05). *Rett Syndrome and exercise.* Retrieved April 19, 2021, from <https://rettsyndromenews.com/rett-syndrome-and-exercise/>