



THRIVING
with RETT



PHYSICAL THERAPY GUIDE

by Meir Lotan,
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My name is Meir Lotan and I am a professor at the Physical Therapy Department at Ariel University in Israel. I have been evaluating and treating individuals with Rett for the past 28 years. During this time I've had the pleasure of working with over 600 individuals with Rett syndrome across the globe.

The importance of physical therapy to individuals with Rett syndrome at all ages cannot be overstated. It is my firm belief that "movement is medication for individuals with Rett syndrome" or in the words of Dr. Andreas Rett, "every opportunity should be taken to encourage active movement."

Ideally a physical therapist will work with your child for an extended period of time and is very in tune with any changes your child may experience. Some issues that should be top of mind include:

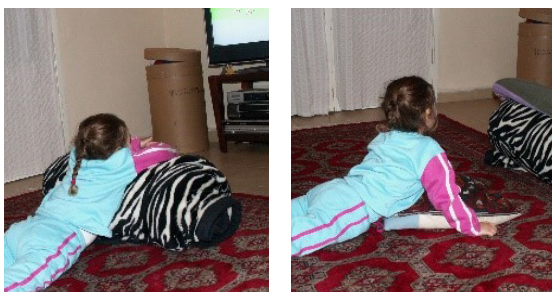
- / tone issues (typically low tone in young children which may become high tone as they age)
- / scoliosis / kyphosis
- / hip problems
- / contractures (elbows, wrists, knees)
- / pronation of the feet
- / toe walking

Therapists will work on functional activities such as walking and going up and down stairs and transitional activities such as sit to stand. Range of motion exercises and careful stretching of shortened muscles are key. Therapists can provide input to facilitate the child's participation in activities like playing in the playground with peers, or going shopping with family members.

While the therapist may work with your child several hours a week Rett is exerting its influence on your child 24 hours a day. Together with your therapist it's ideal to put together a home program that supplements the therapy sessions.

Some examples of activities that can be done at home follow.

- / **Tummy time** – Prone lying and watching TV can be passive (extending the spine – picture on the left) or active (extending the spine while strengthening the hands and working the neck muscles – picture on the right), depending on child's abilities.



- / **Sitting up** – For individuals who spend a lot of sitting in a wheelchair or sofa, sitting at the edge of the sofa or on the edge of a chair or bench is a great way to work core muscles and improve balance. Start with a few seconds and increase duration with time. Be flexible and adapt the duration of the exercise according to your child's abilities (enhance duration when she is feeling great and reduce duration if she is having a bad day).



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- / **Encourage standing** by providing support through leaning on furniture or in a standing frame. Get creative and use the standing time to listen to music or audio books or participate in activities like cooking in the kitchen. This will keep your child occupied in activities she likes, reducing her attention on the difficulty of the activity. Try to enhance the duration of the exercise as she gets better.

/ **Walking in the house and yard.** Challenge your child with stairs, make obstacle courses your child needs to go through on her way to the bathroom, or the kitchen, or on her way to watch her favourite program on the tablet /You tube.



/ **Stepping and dancing to music** – Music is a big motivating factor for most individuals with Rett syndrome. Therefore, dancing can be used to enhance stamina and balance. Let your child and siblings take turns to choose the music. Start with slow music and significant support, and gradually reduce the support and enhance music's rhythm.



/ If the person with Rett Syndrome can't walk by herself, put on music that you both like and dance with the wheelchair or a walker if you have one at home. It's good for morale and it is also good exercise for you.

/ While walking outside tackle sidewalks, different terrains, up and down hills, walk on the beach or in shallow water. Some girls really like the outdoors. If this is the case take long walks, together with other family members and friends.

/ If your child can't walk independently consider a gait trainer placed over the treadmill.

Therapists will also play a key role in helping to identify and procure any durable medical equipment that your child may need (e.g. wheelchair, stander, walker).

A final word:

The genetic limitations that Rett Syndrome puts on our children is not a done deal. We as parents, caregivers and therapists can make the best of the cards dealt and help the child achieve their maximal potential. It is hard work, but so incredibly rewarding.

For further information and resources I can be contacted at: ml_pt_rs@netvision.net.il