

Maximizing the Effectiveness of Physical Therapy

**Katie's Clinic for Rett Syndrome
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Discussion Topics

- Physical therapy guidelines specific to RTT
- Delegation of intervention strategies
- Goal writing
- Scoliosis
- Body mechanics for caregivers
- Other therapeutic interventions

Traditional physical therapy intervention may not maximize outcome for girls and women with Rett Syndrome

- Overemphasis on the Developmental sequence
- Overemphasis on transitional movements
- Decreased functional hand in girls with RTT use impedes floor transitions and crawling
- Difficulty with initiating movement impedes transitional movements
- Functional goals for our girls are different

Girls with RTT require their own specific intervention guidelines

- Emphasize weight bearing through feet early on
- Emphasize weight shifting in standing early on
- De-emphasize floor time
- De-emphasize expectation of independent transitions

These guidelines better structure therapy to the specific need of girls with Rett Syndrome

- High repetition, more time for integration of the motor plan of walking
- Decrease frequency and intensity of heel cord tightening
- Increase bone density
- Transitions may be easier once wt.bearing or walking occurs making our girls feel more secure and motivated to attempt transfers

Treatment strategies should include the use of therapeutic handling techniques

- **Engage the feet**

- assisted pushing off the wall while lying down
- sensory input to feet
 - vibration
 - massage
 - deep pressure
 - water play-different temperatures

- **Offer a variety of weight bearing and weight shifting experiences**

- put shoes on, shoes off, one on one off
- place book, pillow etc., under one foot
- vary alignment of feet in relation to each other
- move in different planes
- dance

Treatment strategies should be tailored for RTT

- Practice sit to stand transfers; don't expect mastery
- Perform stretching exercises to maintain range of motion
- Include trunk strengthening exercises
- Consider adding music to therapy time
- Expect need for a lot of repetition
- Don't oversupport

Treatment strategies should also include the use of adaptive equipment, such as a stander



- (Superstand, adjustable prone/supine stander)
- covered by insurance, schools often purchase
- provides opportunity for weight bearing while being fully supported
- should usually be used with supportive braces

A walker provides the opportunity for supported weight bearing, weight shifting and walking



- (miniwalker)
- covered by insurance, many schools have purchased
- promotes a feeling of independence

An adapted bike offers the opportunity for reciprocal movement patterns of the legs



- Schools sometimes purchase, sometimes (rarely) insurance
- reciprocal pattern is needed for walking
- fun, age appropriate and social activity

Adaptive equipment should provide stability and promote motor exploration



- **Positioning aides**

- strollers
- wheelchairs
- adaptive chairs
 - Wombat, Leckey, Tiger

- **Orthotics**

- SMOs, AFOs ,night splints
- knee immobilizers

Other therapeutic interventions for RTT



- Aquatic therapy
- Hippotherapy
- Gait trainer over treadmill
- Whole Body Vibration (WBV)
 - juvent.com
 - wavexercise.com
 - soloflex.com
- iGallop
- Theratogs, hiphuggers

Every girl is unique, so therapies will differ.

- Generally, little ones under the age of 2 should still have a lot of floor time
- Girls between 2-5 years of age should continue floor time if significant strides have been observed
- Girls over 5 should spend little therapeutic time on the floor
- Orthopedically fragile girls may not be candidates for weight-bearing

A well rounded treatment approach includes the parent/caregiver, therapist, and educator.

At home

- stretch
- massage
- night splints
- supportive positioning
- floor time to relax and stretch

In classroom

- stander
- supportive positioning
- walker

Skilled P.T.

- therapeutic handling techniques
- assessment
- re-assessment
- procuring and adapting of equipment

Effective goal writing is essential since it captures progress over time thus justifying continuation of services

- 3 times weekly P.T. intervention for change
- What do you want for your daughter
- Educate your P.T. regarding RTT
- Make goals quantifiable so even small changes are revealed
 - amount of support, length of time, repetitions

Examples of Goals

- Anna will tolerate tactile input to feet for greater than __seconds __ times daily.
- Anna will bear __% of her weight in standing for __seconds in 3 of 5 trials.
- Anna will tolerate weight bearing through feet with ____ (max, max/mod, mod, mod/min, min, contact guard, stand by) assistance for balance __minutes 3 of 5 trials.
- Anna will push off with her feet while in a walker __times in 30 minutes.
- Anna will accept facilitated (lateral, frontal) weight shifting while in standing with __assistance for __seconds(minutes) 1 of 5 trials.
- Anna will transition from sitting on a chair to standing with ____assistance __ of __ trials.

More Goals

- Anna will walk ___ feet with ___ assistance for (balance, weight shifting, foot placement) ___ of ___ trials.
- Anna will descend greater than ___ steps with 1 hand held in less than 4 minutes.
- Anna will walk over a change in surface type with ___ (max, mod, min) tactile or verbal prompting with hand held assistance in less than 2 minutes.
- Anna will tolerate ___ minutes in a prone stander at an angle of ___ degrees from upright.
- Anna will propel an adapted bike ___ feet in ___ minutes with ___ assistance to (initiate the movement, direct).

Opinions on treatment for scoliosis vary greatly

- Generally a curve of less than 30 degrees is considered mild; over 60 degrees is severe.
- Surgeons will do surgery at 40-50 degree or higher curve
- Debate over effectiveness of
 - Electrical nerve stimulation
 - Exercise
 - Massage
 - Positioning including overcorrection
 - Botox

Bracing may be effective in preventing the progression of a curve

- Dynamic Systems

- Secondskin (Australia)

- Spincor- softer, more comfortable, allows muscles to work, company prefers to brace early

- Dr. Deutchmann 1-800-281-5010 (scoliosissystems.com)

- Not aware of outcome studies on neuropathic scoliosis-ask your orthopedist

- Rigid, passive systems- exert pressure on the back and ribs to push and hold the spine into better alignment

- Boston- popular TLSO
- Milwaukee- original, bulky, has a neck piece
- Charleston- worn only at night
- Wilmington/duPont- also TLSO

Increased physical dependence requires that the caregiver pay special attention to his/her body mechanics

- TAKE CARE of YOURSELF!
- Use your thighs when lifting.
- Keep your back flat and bend your knees
- Keep your daughter close to your body
- Don't twist your torso- move your feet to turn
- Pay attention to your spinal alignment when sitting and feeding your daughter
- Let her do as much as possible- it is good for both of you

Most importantly, enjoy your daughter!
Thank you

