



THRIVING
with RETT

ADVICE & ENCOURAGEMENT

FROM THERAPISTS WHO WORK WITH GIRLS AND WOMEN WITH RETT SYNDROME

What do I tell my daughter's therapists? How do I tell them to work with her? These are common questions. Here is advice from experienced therapists for those who may be working with a girl with Rett syndrome for the first time.



Keep the girls walking and push them to do overhead activities.

DONNA BOWERS | *Physical Therapist*



The biggest recommendation I can give for any therapist is not to be intimidated by the diagnosis. Despite never having worked with a girl with Rett before, I feel as if my nearly 30 years of experience working with other children carries over when treating Gracie. She is a joy to work with, and “something new every day” is not an exaggeration. She is always changing, and therefore flexibility in my treatment approach is probably one of the keys to her success on any given day.

CHRISTINE ALLEN | *Physical Therapist*

The most important advice I can offer is to use a calm, slow approach, especially with any movements. Take the time at each encounter to make an initial face-to-face contact. Establish eye contact while providing a firm but gentle touch to their shoulders or arms. Speak softly or even sing a short song that can be your special song. This gives them time to relax and be prepared for new activities with less anxiety and body stiffness. Be joyful and kind at all times!

MAUREEN B. CARROZZINO | *Physical Therapist*

Research Rett online. Check out this link www.rettuniversity.org (Rett University with Susan Norwell). Connect with other therapists who have worked with children with Rett. Other thoughts:

- / Every child is different, including children with Rett!
- / Don't underestimate a child with Rett – evidence is showing that many have intact cognitive ability with severe motor issues / verbal apraxia / body apraxia and can't communicate for physical reasons (not cognitive). They can potentially learn to read and write using augmentative communication devices.
- / Give children with Rett more time to respond to communication – their motor systems are slow and need more time to process.
- / Just because one type of communication system / device didn't work, it doesn't mean another one won't. Most of the time it is simply trial and error to find out what works for that child.

MIRJANA BELCEVSKI | *Speech-Language Pathologist*



Don't underestimate girls with Rett syndrome. They are very social and have fun personalities – so have fun with them! Be silly, funny, and don't get too focused on the "data." They do much better with entering a conversation (via AAC) once you start talking to them about subjects that interest them.

MELANIE KARPUS |
Speech-Language Pathologist

The advice that I can share is that each girl is trapped inside their body ... and they have a real understanding, feelings, and emotions equivalent to if not greater to what we all have. Their eyes will tell you this, and it's our responsibility as professionals to bring this greatness out.

Be patient, loving, understanding, but also encourage them to do everything they can. You may be surprised at their capacity. Some take more time to process information and act, others may move quickly through space needing a concentration on their breath and energy to slow down and focus. Each girl is different. But the most shining piece of advice I can give is to look for their humor and hear their laugh. It's magical and will inspire you to do great things with and for them!

PEPPER FRANCHINA-GALLAGHER |
Physical Therapist

Rett Syndrome is a diagnosis but it does not define the child. As I shared with Jen on the day that they received Ava's diagnosis, getting the diagnosis did not change who Ava is. I did not alter my therapy approach with Ava at all and I certainly do not let the diagnosis limit what I work on with her. I have always expected Ava to rise to each challenge and have never altered that expectation – before or after she was diagnosed.

SIMONA DEMARCHI | *Physiotherapist*

The most important piece of advice I can offer is this: Be patient, and treat them as though you KNOW they understand. Ask once, give them time, and you will be AMAZED (and sometimes hysterically shocked) by all they have to say. When you least expect it, they will bring tears to your eyes when they show you all they can do when you give them time to process. As therapists, we always have difficulty being quiet – we are trained to cue and repeat. But what I urge of you is to be quiet – LISTEN to these girls, and you won't regret a single moment.

LIZ ROGERS | *Speech-Language Pathologist*

They are smarter than they may first let on. Ruby knows how to get out of work when she wants to, and if you don't push her she knows how to manipulate the situation into not working, just like most kids. Here are some other tips:

- / Give them plenty of time to respond to what you are asking.
- / They almost always have an opinion on what you are asking. Watch closely – it may come in the form of a smile, frown, an exasperated gasp, or an eye roll. It's amazing to see how much these kids have to say when you're watching them closely.
- / Treat them like you would treat any other child. Set boundaries when they are needed, tell them what you are going to do, what the goals are, push them when they need to be pushed, let them rest when they need to rest, and I promise they will surpass all your expectations.
- / Like all kids, they have good days and bad days. Bad days are not necessarily indicative of them heading on a downward spiral.
- / Don't treat them with "kid" gloves. These kids are tough and tolerate more than most adults I know. Don't be afraid to play with them, have fun with them. I promise their smiles will be the best part of your day.
- / Let them know when they have done a great job. There is nothing greater than seeing them beam with pride when they know they have accomplished a goal.
- / Be patient – progress may be slow but that's okay, as long as you keep going.
- / Keep their spine and ribcage as flexible as possible – rotation, rotation, rotation!
- / When it becomes age appropriate to stand it's so important to get them up and standing in A-frames, standers, etc.

ROSEANN PUTHIAMADAM | *Physical Therapist*

These girls understand so much more than we give them credit for. Include them in every conversation. Acknowledge them.

JACKIE WRIGLEY | *Speech Therapist*

Know the patient! Be sure to understand the communication system that the girl or woman with Rett you are treating uniquely uses. Know when she is "talking" to you, and understand when she "hears" you. Look for the slightest signs of what she may be non-verbally communicating to you.

AYANNA MILLER | *Physical Therapist*

Realize how intelligent these girls are, and don't assume that because they are not communicating with you that they don't understand what you are saying. Children with ataxia (a movement disorder associated with Rett syndrome) often fear movement out of their midline base. I tend to explain to Claire what we are going to do and that she is safe. She was my first patient with Rett, and I reached out to other therapists and the internet to learn how to develop a treatment plan for her. I quickly learned that Claire was an excellent teacher as well. I find myself providing her opportunities for movement but also following her lead.

MARRI-JO SOMODI | *Physical Therapist*



Believe in these girls; you have to know they're smart, not just think they're smart. / Don't repeat yourself to girls; give them plenty of time to respond; every time you repeat yourself you are rebooting their system and they're essentially starting over.

AIMEE FINI |
Occupational Therapist + Rett Mother

Read from the websites available on Rett syndrome. Do not fear the student moving through the stages of Rett. If some skills decrease, others may get better (such as eye contact). Be aggressive about starting a voice output communication system before verbal skills decrease.

With parent permission, talk to the student's classmates about Rett syndrome and what they can do to be a good friend. I made a book about why Rett occurs and how to be a good friend in child-friendly language. I focused on more positives than negatives.

Finally, our OT suggested arm splints be worn on a revolving schedule to keep one or both arms straight to keep her hands from always being in her mouth. This assisted in the student being able to do some skills that they could not do with their arms curled and hands to mouth.

KAREN RICHTARIK | *Speech-Language Pathologist*

It is not enough to just take care of them in school. Schooling should intrigue, stimulate, enrich, and educate them, as it should for all students. We know they are interested in us and the world around them, so let's provide the access.

DENISE CLARKE ROMEO |
Physical Therapist + Special Education Teacher

Do research and learn as much as you can about Rett syndrome. Here are a few other recommendations:

- / Be open to suggestions from parents and other professionals.
- / While teaching communication skills, incorporate typical age-appropriate activities and conversation.
- / Employ plenty of wait time.
- / Treat all responses as meaningful, even when unsure if a response was meaningful or accidental.

CATHARINE COSOLETO | *Physical Therapist*

Just like no two people are alike, no two people with Rett syndrome are alike. Each person will differ in strengths and weaknesses, muscle tone, function, and cognition. Work with the individual needs. Don't get too hung up on never having treated someone with Rett syndrome before. Many techniques and strategies that you have learned and used with other patients can be very useful.

HELENA WISTON |
Occupational Therapist



The best advice I can give is to never forget that girls and women with Rett syndrome are first and foremost an individual. These girls are girls first. They like to eat, listen to music, hang out with their friends, go out and about, and enjoy life! They are a joy to know! Health and wellness should be addressed every day. Nutrition and exercise should be part of their daily routine. Keep the girls active and engaged in their environment.

CHERYL UNGARI | *Physical Therapist*

The most important advice I can give PTs working with children with Rett syndrome in the school system is to adapt / modify activities to allow for the child to participate in activities at school with their peers. The other thing I look at is equipment to use with these kids to enhance their participation at school and home. As a PT it is important to monitor range of motion, strength, and independence levels. I also take time to listen to the families. I make it a priority to address the family's goals and priorities.

JENNIFER GODDARD | *Physical Therapist*

The first thing that pops into my mind is to allow a child with Rett time – time enough to process what you are asking their body to do. I learn every time I work with Ruby and other girls with Rett, once I facilitate a movement and I'm ready to help them accomplish it, if I wait 20 seconds longer they suddenly do it themselves. The smile of pride when this happens is indescribable!

AILENE TISSER | *Physical Therapist*

Working with Emma has been a wonderful gift for me personally and professionally. She has taught me so much about myself and about working with children with learning differences. Some quick tips and ideas for others working with girls with Rett syndrome:

- / Rett girls need lots of time to respond.
- / Flexibility is crucial, be willing to try one program or device and try something different if it doesn't work.
- / Honor and respond to any attempts the child makes to communicate.
- / Work diligently to develop the child's receptive language skills with a communication system such as PODD.
- / Assume the child understands everything you are saying. Talk to her and include her in the conversation.
- / Develop a consistent yes/no response system that works for the child.
- / Give lots of opportunities for her to make choices. This will help her feel more in control and empowered.
- / Create lots of opportunities for peer interactions.
- / Be crazy and silly and make lots of mistakes. These girls need to know we are not perfect and we all have things we need to work on.
- / Work closely with the parents, they are integral to any team!

JESSICA E. JAKOBE | *Speech-Language Pathologist*