

Example

Care Notes

General:

Please sit Child arms length from nearest child. She does not hit but tends to be overly friendly.

Always have a hand held or gait belt on her if she is up walking. She has low body awareness and vertigo. She will, in mid step, start walking to the side or backwards. This is normal for her.

We basically use the gait trainer as a stander for things like kicking balls or when someone cannot have a hold of her. We prefer she not be in her wheelchair and be kept mobile unless exhausted or feeding.

Communication:

We are sending a Step by Step Communicator for back and forth conversations and turn taking. She has experience with touch screens, eye gaze, jelly bean switches, big macks and adaptive scissors. She uses Boardmaker and Laurete Software at Home.

Apraxia is her biggest issue. Please wait 30 seconds to one minute for answer. She will answer by batting at or looking at. Make sure the two match. The hands tend to get a little wild.

Be aware that when making choices if one of the choices is red she will make that her answer even if it is wrong. We don't know why.

OT/Speech:

She has no functional hand use and this is the trademark of Rett Syndrome. Please continue therapies but adapt please. She responds well to music and light. Cause and effect toys and learning devices. We are sending along arm braces if hand mouthing is an issue. Try to brace one arm at a time rather than both. Hand mouthing is not something she is doing. It is something that is happening to her.

PT:

She has very low tone and hyper extensive joints. As stated above she gets vertigo and color or pattern changes in the floor. Stretching , core, arm and leg strengthening is most important. Please keep her moving.

We have a bear hug vest as well as a weighted vest if you would like me to send either or both to school to help with body awareness. I prefer they not be worn on hot days. Remember to watch out for her Mic-Key button.

She experiences Rett Tremors. They are described as-Rett patients develop episodes of "shakiness" or fine tremors of the torso and, possibly, the arms and legs, particularly during times of stress or excitement. This is very Parkinsonian in appearance and is a nervous system reaction to anxiety. They are not seizures. She would just need to be seated and calmed.

Feeding:

Her main source of nutrition is by gtube. Remember to vent before and after feeding. We have found that she usually only eats by mouth when there are other children doing the same. We will send along a snack, juice and a cup for her. She prefers her drink and snack cold. Please start my only giving her half of each and don't be discourages if she refuses. Please communicate how much she has taken in to me daily.

Hygiene:

She is incontinent. She will have a BM and urination on the potty if you get her there in time. Timing is the key. Please try to sit her on the potty each day after lunch. She must be strapped on and not left alone. She does, at times get hysterical if she has a BM in her diaper. If you smell or hear flatulence please get her to the potty. Please communicate BM's to me.

She is a hand mouther. Please remember that everything she touches will then go into her mouth. Please wash hands often. If she is sitting on the floor watch hands or have her sit on a clean mat.

Resources:

www.rettgirl.org

This is a very helpful website that we are a very large part of. You will find almost anything you need to know about Rett Syndrome and what works for Rett girls there.

Thank you.