

What I do	What it means	What you should do
Stick hands in mouth	Unknown. This is typical of Rett Syndrome.	Nothing. Occasional splinting can assist me to use my hands more productively and improve my concentration.
Frantic mouthing or rocking	I am highly excited or agitated (bored or annoyed).	Check my facial expression and act as appropriate.
Look at something or hop over to something	I want this. I am choosing this.	Give me what I want e.g. food, drink, swing etc.
Touch something with hand, forehead or nose	As above.	As above.
Move closer to the television	I'm enjoying what I'm watching.	Move me back from the radiation, but don't disturb my viewing.
Bunny hop towards the table at meal time	I'm hungry.	Feed me now.
Turn my head away while feeding	I'm still eating. Yuck!!! I'm just not hungry. I'm too tired to eat.	Wait a while then try again. If I'm still not interested you should stop feeding me.
Smack my lips	I'm thirsty.	Give me something to drink. I need 4 - 6 glasses of water per day.
Stick my head down on the floor.	I'm tired.	Let me sleep.
Look at you	We are sharing this moment. I am here and I get it.  Don't be silly.	Enjoy it.  Stop speaking down to me.
Squeal or laugh	I'm excited!	Enjoy it.
Make noises	I'm attempting to vocalize.	Give me some acknowledgement and stop to chat for a bit. Listen closely so you don't miss an attempt at a real word.
Speak a word or a couplet	Although they are rare, I do have words. I have exerted a <b>massive</b> effort in order to say this thing, and I am a very clever girl!	Make a huge fuss of me. Break out the champagne! Throw a party! Declare a public holiday! Dance in the streets!

<b>What I do</b>	<b>What it means</b>	<b>What you should do</b>
Crying spell	Unknown. This is also typical of Rett Syndrome. The cause may be actual physical pain or mental distress due to brain dysfunction.	Check for obvious sources of pain such as a burn, a bite or tight elastic. Remove my shoes and check my feet for circulation. Massaging and stretching sometimes help. Offer food. If taken early enough, this sometimes forestalls a crying spell. If you suspect constipation, it may help to stand me in an upright position, sit me on the toilet or place me in a warm bath. Occasionally, if something interests or amuses me enough, I can be distracted. Sometimes I am tired, and I just need to get to sleep. In extreme cases, a crying spell can last for up to five hours. If all else fails and I am inconsolable, contact my parents for permission to administer an analgesic. If the crying diminishes in response, it may mean that I should be checked by a doctor. In any case, my parents should be informed when a crying spell has taken place.

Things I Like	Things I Don't Like
<ul style="list-style-type: none"> <li>• Making choices</li> <li>• Eating and drinking</li> <li>• Excursions and outings</li> <li>• Music and dancing</li> <li>• Swimming and bathing</li> <li>• Standing and walking</li> <li>• Horse-riding</li> <li>• Play equipment such as swings, slides, trampolines, see-saws and rockers, bikes, ball pits</li> <li>• Rides such as Ferris wheel, merry-go-round, teacups, mini-train</li> <li>• Television, videos and DVDs</li> <li>• Books and stories</li> <li>• Toys and computers</li> <li>• Games and activities</li> <li>• Parachute games</li> <li>• Light, colour, sound, action</li> <li>• Massage, warmth, touch, aroma, rest</li> <li>• Cuddles and attention</li> <li>• Admiration and praise</li> <li>• Smiles and laughter</li> <li>• People who are funny</li> <li>• Naps</li> <li>• My favourite colour is yellow.</li> </ul>	<ul style="list-style-type: none"> <li>• Getting my hair styled</li> <li>• Movies in cinemas when the sound is too loud</li> <li>• Sudden loud noises</li> <li>• Being stuck in my pusher too long</li> <li>• Being ignored or left out</li> <li>• Being bored</li> <li>• Being treated as if I'm not there and I don't understand</li> <li>• Overtired and over stimulated</li> <li>• Negative emotional currents such as loud arguments, temper tantrums, stress, tension, depression and unhappiness</li> </ul>