

# Building Foundational Communication Support for Individuals with Rett Syndrome



## FIRST STEPS

While a Rett Syndrome diagnosis is overwhelming, there is definite, reportable hope for substantial communication growth and language development. The strategies listed below are ongoing strategies, but essential if you are just beginning. They will support the use of both soft and high tech tools and resources to build more independent communication over time. As with any learning, it will take time and practice on both you and your child's part. Don't give up, look for small intents and celebrate successes. Your child will surprise you with what they want to tell you.

## Three Key Strategies

### 1. MODEL (DEMONSTRATE)

As your child's communication partner, it is critical to model the use of symbols, pictures or objects by communicating to the child using the options themselves.

*For example:* While using symbols "like" and "don't like" point to the symbols and say: "I like, I don't like, then say 'I like' "YES" "I like that book." When offering choices of objects you can say: "Cookie, cracker" holding them up – then say "Cookie – NO" "Cracker – YES" "I want a cracker." By modeling, the individual will learn how to use the symbols, pictures or objects to make simple choices and begin to map (assign) meaning to the symbols. This is the same process we use to teach verbal children. We model and they learn to map the meaning onto the words.

### 2. MAP (ASSIGN)

Map your child's reactions onto available symbols, pictures of objects. An individual will learn the meaning of symbols even faster if you begin with their own feelings and opinions.

*For example:* If you see them smile at a picture say: "Like" (point to the like symbol) or "YES, you are telling me you like the picture." This is particularly helpful for someone who is just beginning to learn to communicate and does not have a clear "YES" response established yet. In the same way, if they smile and look at their juice, you say "I can tell you want your juice, you looked right at it and smiled – you like your juice" and you can give her the juice and show her the "like" symbol.

TIP: It is particularly important to "map meaning" onto the "HELP" symbols to replace behavior with communication.

### 3. SELF-EXPRESSION

Now your child will begin to beat you to the punch! They will look to a symbol, or quickly smile and look at their juice. You will hold up a symbol or picture to model and they will eye-point to what they want to say. When you start to notice their initiation or responses, it is a time to celebrate. "Look at you, you told me just what you wanted." "Wait a minute, you don't like that monster either?" Be specific in your praise so they know exactly what they did that worked. "You looked at your juice and LIKE – you know what you like." It is at this point you will want to add to her language set and explore technology and additional tools and resources to support their growing communication skills.

## Avenues for Building Communication

There are three main areas that support language growth and development for all children and have also proven successful for individuals with Rett Syndrome.

### **Language immersion throughout everyday experiences**

Bathing, eating, changing their clothes and anything else you can think of are opportunities to build vocabulary and language. They can communicate "like or don't like" for their outfit that day. "More or done" for lunch. "Bath or Book" first as a bedtime routine.

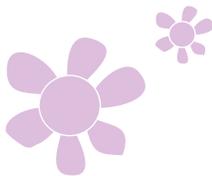
### **Through play and interaction**

There are some great iPad apps available that do not require a lot of hand use. Toca Boca apps are great for offering choices as the choices are spread apart and easy to read for eye-pointing and for saying the choices and waiting for their "YES."

### **Through controlled vocabulary of literacy-based experiences in order to experience and retell**

Reading to your child is a proven way to build communication and vocabulary. In the beginning, just watch where they look and read that as their pointer. Have a mini-conversation about it. "You spotted that girl's hat – it is really big." Later you can add a "like or don't like" so she can give an opinion.

There is no formal way to begin. It's recommended you just start using these strategies in daily conversations and build upon them over time. Be kind to yourself and realize both you and your child are learning a new way to communicate. They are present and understand everything they hear and everything you say. Work to include them in every conversation. Learn to talk with them and not at them. With your help and the help of those around them, you will begin to see them start communicating in real and tangible ways.



RETT UNIVERSITY

[www.rett-u.org](http://www.rett-u.org)

BY GIRL POWER 2 CURE