

THRIVING *with* RETT



COMMUNICATION GUIDE by Jennifer Facchinelli

Having your child be diagnosed with Rett Syndrome is devastating and can often make parents feel like they are powerless to help their child. However, there is one area where parents can have a huge impact on the life of their child, and that's communication.

While the majority of individuals with Rett Syndrome are non-verbal, they do possess the ability to learn to communicate, learn literacy skills, participate at school, and make friendships and connections with the people in their lives.

The road to communication is long and bumpy but it's one that's being traveled successfully by many individuals with Rett. Here are some pointers for those at the beginning of the journey:

1 / Start the process of getting a device/system.

High-tech devices such as a Tobii or PRC can provide life-changing independence but might take some finagling to get. The process of getting one will be different depending on where you live. Generally, there are three options: government prescribed, insurance, or self-funded. For more information on how to get a device, contact your child's physician, Rett clinic, speech language therapist, assistive technology specialist, and/or inquire with other local families. While you are applying for a high-tech device you can get started with a paper-based system (low-tech system). Your child does not need to be proficient with a paper-based system before getting a high-tech device.

2 / Make sure the device has a robust communication system that will allow your child to say whatever they want to say. Many people will have opinions on which system is the best but the truth is the best system is the one you use. It's tempting to only have a few buttons for your child at first, but your child has more to say than a few words; they need to have access to all the words in order to learn to use them. Having



Many people will have opinions on which system is the best but the truth is the best system is the one you use.

only a few buttons might also deter your child from using the device; if they can only say what you want them to say they might choose to stay silent!

3 / Believe your child can learn but understand that it likely will not happen overnight. Learning to

communicate is a long process and it's not perfect but know that if you don't try it won't happen. It's hard work and takes lots of practice. You might have heard the phrase "presume competence" which means that your child can learn. However, they need explicit instruction in order to learn. Think of it like a musical instrument – you possess the ability to learn how to play the violin but if nobody teaches you how to play (or if they leave the violin in the case without taking it out for you to practice with) you won't be able to make music.

4 / Understand that you are your child's number one teacher. You need to model whichever system you choose and show your child how to use it by

You need to model whichever system you choose and show your child how to use it by communicating with it.



communicating with it (in other words: press buttons on the device when you talk to your child; it doesn't have to be every word, even one or two in a sentence will help). Respond to everything they say and if it doesn't make sense give it some context so that it does; this way they can learn to make their selections meaningful.

5 / Cut yourself some slack. This stuff is hard, draining, and sometimes very frustrating. It's cumbersome to take it along everywhere, it's heavy, tech problems can ensue. You'll see other kids doing great and wonder why your kid isn't progressing at the same rate. There will be times where you can't make heads or tails of what they're saying. But don't give up. It's a process with highs and lows. Keep at it at a pace that makes sense for you and for your child. Nothing is more empowering than being able to communicate; for your child to say "I love you" but also to say "stop it" or "you're embarrassing me" or to spell their first word.

6 / Take video as often as you can; this will not only help others to understand how he/she communicates but will also serve as inspiration for you on dark days; sometimes it's hard to see progress day to day, but if you have the ability to look back a few months or years prior, you will see how far your child has come.

7 / Giving your child the opportunity to learn to communicate and be literate can happen at the same time as supporting Rett Syndrome research.

It's not a one or the other thing. We all want for our kids to be free from the symptoms of Rett Syndrome but while we wait for that day to come, we need to empower our kids to take control of their lives right now. Learning to communicate does not happen with a miracle pill you swallow. But with lots of work your child can learn to communicate, have a voice and a say in their everyday lives, and maybe even one day give input into the research that will lead to treatments and maybe even a cure.

Here is a list of resources/websites that can help you along on your journey:

Rett University: www.rettuniversity.org

UNC School of Medicine, Center for Literacy and Disability Studies:
<https://www.med.unc.edu/ahs/clds/>

Rett UK: <https://www.rettuk.org/resources/resources-for-families/communication/>

Rett Syndrome – Communication and Literacy for Children (Facebook Group):
<https://www.facebook.com/groups/1587583214805473/?ref=share>

PrAActical AAC: <https://praacticalaac.org>

Tobii Dynavox: <https://www.tobiidynavox.com>

Prentke Romich Company (PRC): <https://www.prentrom.com>

Smartbox: <https://thinksmartbox.com>

Simplified Technology, PODD Communication Books: <http://www.lindaburkhart.com/podd.htm>