

# RETT SYNDROME

## AND COMMUNICATION

### What *is* Rett Syndrome?

- A genetic disorder that affects brain development
- Occurs primarily in girls
- Development appears normal until around 6-18 months of age
  - At 6-18 months, development slows down
- Characterized by 4 stages (*described below*)
- This syndrome affects:
  - Cognition (e.g. attention, memory)
  - Motor control
  - Behavior
  - Communication skills

### Signs and Symptoms

- Typical development until 6-18 months
- Changes that occur in child's development might include:
  - Loss of words that the child used to say
  - Loss of hand function; hands brought close to middle of the body
  - Loss of muscle tone and delays in motor milestones (e.g. crawling, sitting)
- Smaller head size
- Each stage has characteristic signs (*described below*)

## The 4 Stages of Rett Syndrome and Common Signs

### Stage 1: Early Onset (begins between 6 - 18 mo.)

Physical: loss of muscle tone; motor delays (e.g., crawling or sitting)

Behavior: reduced interest in toys and play activities

Communication: slowing of verbal communication; reduction in eye contact

### Stage 2: Rapid Destructive (begins between 1 and 3 yrs)

Physical: slowed head growth; unsteady walking (e.g., on tip-toes, having wide-base, having stiff legs)

- loss of purposeful use of hands; may have “wringing” or “hand washing” movements

Behavior: irritability; self-abusive behaviors; screaming tantrums

Communication: loss of desire to interact with others; previously learned words disappear

### Stage 3: The Plateau (begins between 2 and 10 years)

Physical: motor planning difficulties; seizures; scoliosis begins to show (curving of the spine); jerky movements of trunk

Behavior: less crying; more interest in social interaction; alert of surroundings

Cognition: severe cognitive impairment

### Stage 4: Late Motor Deterioration (begins around 10 years and lasts for life)

Physical: extreme scoliosis; muscle weakness; abnormal posturing; inability to walk

Behavior: attentive and alert

Communication: communicates with eye gaze

**For more information, visit:**

[www.rettsyndrome.org](http://www.rettsyndrome.org)

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### Communication in Children with Rett Syndrome

Children with Rett syndrome will be unable to produce speech. However, children are still able to communicate by using eye gaze, body movements, and alternative communication devices (e.g., picture boards or electronic devices).

It is not always easy to recognize what a child is trying to communicate through these alternative communication methods, so it is important to train communication partners on how to interpret the child's interactions. A speech-language pathologist plays an important role in supporting the communication of a child with Rett Syndrome.

#### Roles of the Speech-Language Pathologist

- Train communication partners (including caregivers and teachers) on how to recognize communication attempts and how to respond
- Teach children to “point” with their eyes to indicate choices or desired items
- Teach children how to use alternative communication (e.g., picture boards, electronic devices)

#### Roles of Communication Partners

- Recognize any attempt to communicate including eye gaze, body movements, and spontaneous vocalizations
- Wait at least 30 seconds for the child to respond to you
- Interpret the child's behavior as meaningful and intentional
- Create opportunities for children to initiate communication

### Communication in Children with Rett Syndrome

#### At school:

Teachers and speech-language pathologists can incorporate therapy into meal times. If the child uses a communication device, make sure to have it present and easily accessible. Present the child with food choices and wait until they initiate a response before providing them with an item. Attend to their body movements and what they “point” to with their eyes. This type of exchange can be incorporated into the classroom or at home.

#### At home:

Storybook reading has been found to encourage communication between caregivers and children. Have the communication device in front of the child. The caregiver can point to symbols on the device that relate to the story.



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