



RETT SYNDROME Communication Guidelines

RETT SYNDROME Communication Guidelines:

A handbook for therapists, educators, and families



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Erratum: December 2020

Introduction, page 4: reference to “Appendix 6” was corrected to “Appendix 5”.

Section 4, page 27: “decreasing” was deleted in the heading “Fatigue, alertness, sensory regulation, stress and anxiety” so that the format was consistent with other headings in this section.

Section 8, page 51: “making” was corrected to “making choices” in the Communicative Functions text box.

Section 8, page 62: reference to “Appendix 2” was corrected to “Appendix 5”.

Appendix 1, pages 75, 79, 81-82, 84, 86-88: format was amended to aid clarity (line spacing and headings).

Appendix 3, pages 93-96: AAC Profile and ACETS were added; TASP and VB-MAPP were removed; and C-BiLLT entry was revised.

Acknowledgment from Authors

Many thanks to everyone who has contributed to the development of these guidelines. This project has been a joint effort by many people over a number of years and a truly international collaboration, an example of the teamwork that is such a key element in communication assessment and intervention.

Developing language and communication is a lifelong process, and we hope the guidelines shared in this handbook will support individuals with Rett syndrome, their families, and the professionals working with them as they make that journey together.

Gillian Townend
Theresa Bartolotta
Anna Urbanowicz
Helena Wandin
Leopold Curfs

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As the International Rett Syndrome Foundation (known today as Rettsyndrome.org), we are proud to be a part of bringing this global research initiative to life for families affected by Rett syndrome and the community that is committed to helping them achieve more. The work of Gillian Townend, Theresa Bartolotta, Anna Urbanowicz, Helena Wandin, Leopold Curfs, and many other researchers and contributors is an excellent representation of the dedication and commitment to improving the quality of life for our children and loved ones living with Rett syndrome. It is our honor to support these distinguished researchers. We are grateful for their work.

We remain unwavering in our commitment to empowering you today while working to transform your tomorrow.

Table of Contents

Foreword	2	Section 7: Assessment of AAC System/Device	46
Introduction	3	Trial Periods as Assessment for an AAC System or Device	47
Section 1: Guiding Principles	6	Assessment of Device-Specific Features	48
Rights of the Individual with Rett Syndrome	7	Section 8: Intervention	50
Beliefs and Attitudes.....	10	General Principles for Intervention	51
Section 2: Professional Practice	12	Developing Goals for Intervention	54
Principles of Teamwork	13	Targets and Goals for Intervention.....	55
Responsibilities of Professionals.....	14	Communication Functions	58
Rett Syndrome Specialist Clinics and Expertise Centers	15	AAC Systems.....	58
Section 3: Features of Rett Syndrome and Coexisting Conditions	16	Developing Vocabulary.....	62
Features Associated with Main or Supportive Clinical Criteria.....	18	Choosing and Organizing Vocabulary.....	63
Coexisting Conditions.....	20	Access Methods.....	66
Section 4: Strategies to Optimize Engagement	22	Reading and Writing.....	70
Attitudes and Behaviors of Communication Partners	23	A Final Word on Intervention Techniques.....	72
Strategies Targeting Internal Factors that May Impact Communication.....	26	Appendices	74
Additional Considerations	30	Appendix 1: Statements and Recommendations	75
Section 5: Assessment	32	Appendix 2: Glossary of Terms	90
General Principles of Assessment.....	33	Appendix 3: Resources for Assessment of Communication	93
Assessment of the Individual	35	Appendix 4: Resources for Development and Tracking of Communication Goals	97
Assessment Procedures.....	36	Appendix 5: Links to Useful Websites and Organizations	98
Standardized Assessment or Dynamic Assessment?.....	36	Appendix 6: Advisory Group and Expert Panel Members	100
Other Considerations for Assessment.....	39		
Section 6: AAC Assessment	40		
Starting Point - Assessment of Readiness for AAC	42		
Components of AAC Assessment.....	42		
Models of Best Practice for AAC Assessment	43		
Assessment of Readiness for Eye-Gaze Technology	44		

All websites listed in this book can be accessed online at communication.rettssyndrome.org.

Foreword

When she was a year old, she spoke her first few words. When she was diagnosed with Rett syndrome 18 months later, she had completely lost her ability to speak. How was she to communicate her wants, needs, feelings, and opinions now?

For many families living with Rett syndrome, finding a way to communicate is one of their most challenging issues. Learning how to use augmentative and alternative communication (AAC) and learning how to facilitate their loved ones to maximize their potential takes belief in their abilities, a great deal of effort, and lots of support. Seeking knowledge and skills on how to adjust assessments and how to manage communication, parents (and professionals) find themselves in need of expert support, in need of a shared vision of how to approach these aspects. Yet, so far, little evidence-based guidance has been available to them.

To do justice to the specific challenges of Rett syndrome, such as apraxia, breathing disorder, and epilepsy, a broad consensus on assessment, intervention, and long-term management of communication is needed – for research as well as daily communication and education. The collaboration between parents, caregivers, professionals, and experts in the field of communication for Rett makes these international guidelines the valuable document that is presented here. These guidelines are an important step forward in enabling people with Rett syndrome to communicate more effectively.

Many girls, now teenagers and adults, have moved on from learning to use a few pictos to using a combination of low tech and robust vocabulary on eye-gaze devices. Young girls and boys are starting out with eye-gaze-controlled communication systems. They are learning to communicate, to tell us their wants, needs, feelings, and opinions. It is exciting to see how new possibilities are helping to change our perspective on their cognitive abilities.

Many thanks to the project team, to all the committed communication specialists and parents and caregivers who contributed to these guidelines. Our beautiful daughters and sons with Rett syndrome may be unable to use their own voices to speak, but surely these guidelines will help them move forward in communicating their needs and opinions and in speaking their minds.

On behalf of all Rett parents everywhere,

Mariëlle van den Berg

Chair, Rett Syndrome Association Netherlands (Nederlandse Rett Syndroom Vereniging)

Introduction

Background

Rett syndrome is a neurodevelopmental disorder affecting approximately 1 in 10,000 females. It occurs rarely in males. It is often associated with severe physical and communication disabilities. In most cases, the cause of Rett syndrome is linked to a mutation in the methyl-CPG-binding protein 2 (MECP2) gene.

Why we developed the communication guidelines

A severe disruption in communication skills is one of the characteristic features of Rett syndrome. This has a fundamental impact on the quality of life for individuals with Rett syndrome. Although the literature on best practices in communication assessment and intervention in Rett syndrome is growing, caregivers around the world continue to report their struggle to access appropriate, knowledgeable, timely, and ongoing assessments, interventions, technology, support, and advice tailored to the specific communication needs of the person with Rett syndrome. Communication professionals also report challenges in finding the information, training, and support they need to build up their knowledge and expertise in this area. Therefore, we developed the communication guidelines presented in this handbook to help caregivers, communication professionals, and others support the communication development of individuals with Rett syndrome.

How we developed the communication guidelines

The idea of creating guidelines came into being when we, a small group of motivated professionals working in the field of Rett syndrome and communication, joined together following the 3rd European Rett Syndrome Conference in Maastricht, The Netherlands, in October 2013. With funding from Rettsyndrome.org, we devised and led a project to develop the Rett Syndrome Communication Guidelines.

The project involved reviewing the literature and conducting surveys to identify best practices in the assessment, intervention, and longer-term management of communication in individuals with Rett syndrome around the world. Around 650 people from 43 countries participated in the project, with 490 caregivers and 120 communication professionals completed the surveys, and 36 professionals and parents forming our expert panel. As the project team, we developed draft statements and recommendations based on the findings of the literature reviews and the survey responses from caregivers and professionals. The draft statements and recommendations were then reviewed twice by our expert panel. The panel provided feedback to the project team, and we revised the statements and recommendations until consensus was reached. The final set of statements and recommendations that reached consensus became the Communication Guidelines. This means that these guidelines are firmly based on findings from the available literature combined with expert opinions from professionals and caregivers around the world.

The purpose of this handbook

This handbook was designed to share the recommended guidelines for the assessment, intervention, and longer-term management of communication in individuals with Rett syndrome and to provide relevant background information for caregivers and professionals. These guidelines are intended for all individuals with a diagnosis of typical or atypical Rett syndrome, both male and female, wherever they were born and wherever they live. The guidelines were created to be adaptable to different situations and circumstances. They do not offer step-by-step instructions that people in all countries and services must follow and apply in an identical way. They aim to provide basic information that families around the world can share with therapists and educators to enable any individual with Rett syndrome to meet their full communication potential.

How to use this handbook

The handbook is divided into eight sections, with information and recommendations relating to the following: (1) guiding principles; (2) professional practice; (3) features of Rett syndrome and coexisting conditions; (4) strategies to optimize engagement; (5) general communication assessment; (6) AAC assessment; (7) assessment of AAC system/device; and (8) intervention.

The handbook can be used in many different ways. It can serve as a guide for designing assessments that reflect best practices and enable teams to develop goals that are functional and meaningful. It can provide strategies for families and therapists to advance the communication skills of any individual with Rett syndrome. The handbook provides information on how to get started with communication as well as how to progress the skills of more experienced communicators. There is also key information that describes how the unique features of Rett syndrome may impact communication. Individuals looking for information on specific topics can consult the Table of Contents at the front of the handbook. Other readers who are new to Rett syndrome may find that the early chapters provide a foundation of information to help them as they begin their work with an individual. The handbook can serve as a tool for educating people about Rett syndrome and for advocating for the communication services and support they need.

Throughout the book, the guidelines are presented in several formats. Some are shown in boxes that stand out from the text; others are embedded within the text. All are equally important. The ‘raw’ guidelines (the complete, final set of statements and recommendations that reached consensus) are presented as tables in Appendix 1 at the back of the book.

Quotes from the caregivers’ and professionals’ surveys and from the expert panel are included throughout the handbook to highlight important information. Photographs of individuals with Rett syndrome illustrate a broad range of communication systems and settings, and short stories offer “A Parent’s Perspective” on different stages of the communication journey. We are indebted to the many families who have graciously shared their photographs and their stories with us and are grateful to the even greater number of caregivers and professionals who took time to complete the surveys and engage with the project on multiple levels.

Links to a number of resources and useful websites and organizations are given in Appendix 5. This list is not intended to be exhaustive and will vary according to country and language. It is recommended, therefore, that each country produce its own list to supplement the Appendix. As far as possible, technical language is avoided in this handbook. Where this could not be avoided, the definition is usually given the first time a term is used. However, the Glossary of Terms on page 90 (Appendix 2) may also be helpful as you read through this book.

Language note:

1. In this handbook the term “individuals with Rett syndrome” is used. In some places this is shortened to “individuals” to make the sentences easier to read. Therefore, it is important to remember while reading the handbook that “individuals” always means “individuals with Rett syndrome.”
2. In some places the gender neutral “they,” “their,” or “them” is used, but in other places “she” or “her” is used. This is not intended to exclude males with Rett syndrome, and everything in this handbook should always be read as applying to both males and females with Rett syndrome.

FEATURES OF RETT SYNDROME AND COEXISTING CONDITIONS THAT CAN IMPACT COMMUNICATION

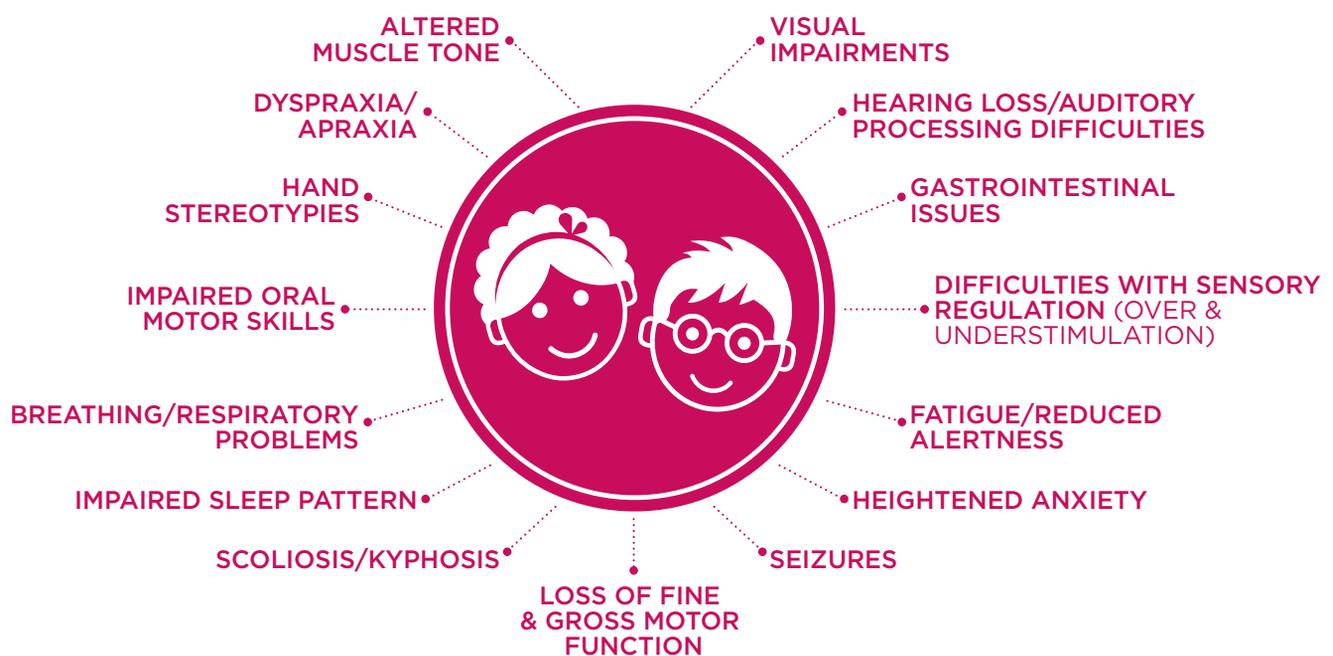


“Expect inconsistency”

Features of Rett Syndrome and Coexisting Conditions That Can Impact Communication

Rett syndrome affects multiple body systems and functions. A number of features have been identified as core or supportive criteria for the diagnosis, including the complete or partial loss of acquired spoken language.¹ Other conditions also commonly coexist with Rett syndrome. Many of these (for example, breathing irregularities, epilepsy, and heightened anxiety) can impact communication (see Figure 3). However, each individual with Rett syndrome is unique — features and coexisting conditions may manifest differently in different people, in different settings, and at different times; not all of the features and conditions outlined below may appear in any one individual, or they may appear with differing levels of severity at different times during an individual’s lifespan.

FIGURE 3: FEATURES OF RETT SYNDROME AND COEXISTING CONDITIONS THAT CAN IMPACT COMMUNICATION



Outlined in this section are brief descriptions of the main features of Rett syndrome and coexisting conditions, along with their possible impact on communication. Strategies for dealing with/reducing their impact can be found in Section 4.



“All of these impact communication but do not limit an individual with Rett syndrome from reaching or demonstrating his/her communication potential. Just need to support their communication with these in mind.”

Expert panel

¹Neul, J., Kaufmann, W.E., Glaze, D.G., et al. (2010). Rett Syndrome: Revised Diagnostic Criteria and Nomenclature. *Annals of Neurology*. 68(6), 944-950.

Features Associated with Main or Supportive Clinical Criteria

Movement disorders

Hand stereotypies and loss of fine motor skills

Stereotypic hand movements — such as involuntary hand wringing/squeezing, clapping/tapping, mouthing, and washing/rubbing — are one of the main clinical criteria for Rett syndrome. Complete or partial loss of acquired purposeful hand skills is also a main clinical criterion for Rett syndrome.

Impact on communication:

Hand stereotypies and/or the loss of purposeful hand skills can make it difficult for an individual to use their hands for communication. They may be unable to point, pick up objects or pictures, or push a switch or buttons, or they may do so inconsistently/unreliably. This will also limit their use of hand gestures, and manual signing is unlikely to be a realistic or successful communication method. Use of a manual exchange system (e.g., Picture Exchange Communication System, PECS) is also unlikely to be an appropriate way for most individuals with Rett syndrome to communicate, and most will find use of a Speech Generating Device (SGD) with touch access difficult or will need to use a more limited set of options if using touch access.

Loss of gross motor skills

Impaired (dyspraxic) gait or absence of walking is one of the main clinical criteria for Rett syndrome.

Impact on communication:

When an individual is unsteady on their feet and/or is unable to walk unaided, their ability to explore their environment and initiate interactions with others is likely to be reduced. They are likely to be reliant on others to approach them to begin a conversation and to help them explore unless they are able to access an SGD to help them call for attention and initiate interaction/conversation.

Dyspraxia/apraxia

Dyspraxia and apraxia are terms that are often used interchangeably. Dyspraxia means a difficulty in converting an intention into an action, while apraxia is a complete inability to convert an intention into an action. One result is that an individual has difficulty or is unable to perform motor tasks on command. The breakdown may be at any stage of the motor-planning process.

Impact on communication:

While dyspraxia and apraxia are recognized as affecting the motor skills of individuals with Rett syndrome, dyspraxia and apraxia can also have a severe impact on learning ability and communication. It may take an individual more time to respond and sometimes they may be unable to respond at all. This does not necessarily mean they have not understood the task but that the problem is with the execution of the task.

Altered muscle tone

Altered muscle tone is a supportive criterion for Rett syndrome. Individuals may have high tone (hypertonia), low tone (hypotonia), and/or involuntary movements (dystonia). Hypertonia and hypotonia can affect an individual's positioning and their ability to move affected muscles. With dystonia, an individual may experience involuntary spasms and contractions, with writhing, twisting movements in any part of their body and/or altered posture. Episodes can last for varying lengths of time and cause varying degrees of pain. Generalized hypotonia may also cause fatigue.

Impact on communication:

Altered muscle tone has an impact on an individual's ability to engage in communication and on their positioning for communication. They may also become 'locked' in a dystonic posture which freezes their movement for a period of time, thereby reducing their ability to interact with other people.

Oral-motor skills

Oral-motor skills may be affected by dyspraxia, apraxia, and/or altered muscle tone.

Impact on communication:

Oral-motor dysfunction can limit an individual's ability to communicate through oral speech. It can also affect eating and drinking.

Please note, eating and drinking are outside the scope of this handbook, but nutritional status can impact levels of alertness as well as overall health. *If oral intake is affected, the individual and their caregivers should consult with an SLP or other feeding specialist for advice on the safety of oral feeding and the need for alternative feeding/nutritional intake.*

For more information, refer to the Nutritional and Digestive Health booklet² and the Growth and Nutrition in Rett Syndrome checklist³ produced by the Telethon Kids Institute in Perth, Western Australia.

Breathing/respiratory irregularities

Breathing disturbances when awake are a supportive clinical criterion for Rett syndrome. Common irregularities in Rett syndrome include breath holding, hyperventilation, and air gulping (which can lead to abdominal bloating). Breathing irregularities may also trigger seizures or be a sign of anxiety.

Impact on communication:

Breathing and respiratory difficulties can make it hard for individuals with Rett syndrome to speak. They can also prolong response time (e.g., while an individual is caught in a breath hold, their whole body may go rigid).

Impaired sleep pattern

Impaired sleep pattern is a supportive clinical criterion for Rett syndrome.

Impact on communication:

A lack of quality sleep can make it hard for individuals with Rett syndrome to be alert and to concentrate. Individuals may take longer to respond when tired.

Scoliosis and kyphosis

Scoliosis and kyphosis are supportive clinical criteria for Rett syndrome. Scoliosis occurs when there is a side-to-side deviation in the alignment of the vertebrae in the spine. This may affect around 80% of individuals with Rett syndrome. Kyphosis is the excessive outward curvature of the spine, causing hunching of the back. Among other reasons, scoliosis can occur as a result of altered muscle tone.

Impact on communication:

Scoliosis and kyphosis can make it hard for the individual with Rett syndrome to access AAC. Kyphosis can also make it hard for the individual to engage in eye contact and for the communication partner to read their facial expressions. Scoliosis and kyphosis can be painful and cause secondary issues (due to compression of the lungs and other internal organs).

For further information, see the Scoliosis in Rett Syndrome booklet⁴ produced by the Telethon Kids Institute in Perth, Western Australia.



“Motor impairments can make positioning extremely difficult for AAC.”

“Apraxia is the biggest problem!! Teachers often don't think that Rett-girls know a lot, but [they] cannot show it because of apraxia.”

Professional

² Downs, J., Leonard, H., Croft, D., et al. (2013). *Nutritional and Digestive Health: An Information Booklet for Families and Carers*. Telethon Institute for Child Health Research. Perth, Western Australia. https://rett.telethonkids.org.au/siteassets/media-docs---rett-syndrome/growth_and_nutrition-booklet.pdf

³ Downs, J., Leonard, H., Croft, D., et al. (2013). *Growth and Nutrition in Rett Syndrome: Checklist for Clinicians on Assessment and Management*. Telethon Institute for Child Health Research. Perth, Western Australia. https://rett.telethonkids.org.au/siteassets/media-docs---rett-syndrome/guidelines_nutrition_and_growth.pdf

⁴ Downs, J., Bergman, A., Carter, P., et al. (2009). *Scoliosis in Rett Syndrome: A Collaboration Between Parents, Clinicians and Researchers*. Telethon Institute for Child Health Research. Perth, Western Australia. https://rett.telethonkids.org.au/siteassets/media-docs---rett-syndrome/scoliosis_booklet.pdf

Coexisting Conditions

Seizures

Sixty to eighty percent of individuals with Rett syndrome are reported to have seizures, though more may have an abnormal EEG recording without other evidence of seizures. Epilepsy often begins around 4/5 years of age in individuals with typical Rett syndrome. There is a huge variation in the type and frequency of seizures. Sometimes individuals are described as having ‘Rett episodes’ or non-epileptic seizures. These may be related to breathing/respiration and/or other autonomic disturbances.

Impact on communication:

Frequent seizures will reduce an individual’s opportunities for interaction, especially as they may be extremely fatigued and need to sleep a lot following a seizure. Two common side effects of medication to control seizures are fatigue/tiredness and reduced alertness.

Fatigue and reduced alertness

Fatigue and/or reduced alertness may be due to any number of factors or the interaction of several factors. These include low quality/disrupted nighttime sleeping, seizures, side-effects of medication, poor nutritional status, and difficulties with sensory regulation (especially, low levels of sensory stimulation – see below).

Impact on communication:

An individual will be less aware of the people, environment, and activities around them, and less likely to be in a state of readiness to communicate or learn when they are tired/fatigued and/or less alert.

Difficulties with sensory regulation

Sensory regulation is the ability to adjust or regulate alertness depending on the levels of stimulation in the surrounding environment and/or the sensory stimuli presented. Individuals may experience difficulties with over and/or understimulation.

Impact on communication:

Some individuals may require a lot of sensory stimulation to arouse them/get their body into a state of alertness so that they are ready to engage; others may be easily overstimulated so that their bodies become overloaded and shut down, needing a period of calm before they can reengage.

Mood and anxiety

Generalized anxiety levels are often reported to be higher in individuals with Rett syndrome compared with their neurotypical peers. Rapid breathing, breath holding, and increased hand wringing behaviors may be signs of increased anxiety. Episodes of anxiety can also increase the likelihood of dystonia and seizures. A large number of individuals, especially in adulthood, are reported to experience problems with low mood and depression.

Impact on communication:

Anxiety, stress, low mood and depression may all reduce the individual’s willingness and desire to communicate.



“After seizures she sleeps a lot... sometimes there is no communication at all for even three days because she is nearly unconscious.”

Caregiver

“I think that seizures can have an impact on their communication in a way where they become tired/exhausted after a seizure.”

Expert panel

“Extreme variation in arousal alertness, sometimes able to scan several items on a page, navigate between pages and answer complex questions, other times frozen [by] fatigue and cannot imitate action on response.”

Professional

Gastrointestinal issues (GI)

Common GI issues in individuals with Rett syndrome can include reflux, abdominal bloating, constipation, and/or diarrhea, with associated abdominal pain.

Impact on communication:

Many parents often report that sometimes an individual with Rett syndrome appears to be in pain but is unable to communicate exactly where the pain is or how severe it is. This is often thought to relate to GI issues. Being in pain and discomfort as a result of GI issues may also reduce an individual's readiness to interact and overall level of engagement with others.

For further information, see the Gastro-intestinal Disorders in Rett Syndrome checklist⁵ produced by the Telethon Kids Institute in Perth, Western Australia.

Hearing-related conditions

As with the general population, individuals with Rett syndrome may experience hearing loss and/or auditory processing difficulties.

Impact on communication:

Any level of hearing loss or difficulty with the processing of auditory information will affect an individual's ability to understand and respond to the speech of others.

Vision/sight-related conditions

Impaired visual acuity

As with the general population, individuals with Rett syndrome may suffer from impaired visual acuity—i.e., a reduction in clarity or sharpness of vision that can be corrected by wearing glasses. An impaired visual field may also cause problems—i.e., a reduction in the area of sight, especially to the sides (peripheral vision) while focusing on a central point.

Cortical visual impairment (CVI)

Some individuals with Rett syndrome may suffer from CVI, a form of visual impairment caused by problems with the visual cortex and pathway in the brain rather than a problem with the eyes. Vision can be variable. Individuals with Rett syndrome can have difficulty with depth and field of vision, interpreting visual images, and distinguishing items when there is a lot of visual 'clutter' in the background.

Oculomotor apraxia

Oculomotor apraxia is also sometimes reported in individuals with Rett syndrome (i.e., a reduction in the voluntary control of purposeful eye movements). Recent research indicates, however, that individuals with Rett syndrome demonstrate the same range of movements as their neurotypical peers although they may be a little slower.

Impact on communication:

Individuals with Rett syndrome may have difficulty in seeing items clearly or interpreting visual symbols. This will affect the choice of appropriate AAC system (e.g., whether picture symbols can be used and if so, the style, size, number, color, and complexity of the symbols chosen). Attentional issues may also affect the ability to track, fix, maintain, and shift gaze which could impact interaction with others and the environment, as well as the ability to learn through observation.

Use of eye gaze for communication is, however, generally considered to be a strength in Rett syndrome, with “intense eye communication—eye pointing” being one of the supportive clinical criteria for diagnosis of typical Rett syndrome.

⁵ Downs, J., Leonard, H., Croft, D., et al. (2013). *Gastro-intestinal Disorders in Rett syndrome: Checklist for Clinicians on Assessment and Management*. Telethon Institute for Child Health Research. Perth, Western Australia. https://rett.telethonkids.org.au/siteassets/media-docs---rett-syndrome/guidelines_gastro_intestinal.pdf

