



RETT SYNDROME Communication Guidelines

RETT SYNDROME Communication Guidelines:

A handbook for therapists, educators, and families



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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.

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Theresa Bartolotta
Anna Urbanowicz
Helena Wandin
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We remain unwavering in our commitment to empowering you today while working to transform your tomorrow.

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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.

PROFESSIONAL PRACTICE



“The team should share a common vision.”

Professional Practice

Principles of Teamwork

Principles of Teamwork

Every individual with Rett syndrome should be supported by a multidisciplinary team.

Where possible, the team should incorporate all significant communication partners and may include the following:

- The individual with Rett syndrome
- Parents and other family members
- AAC specialists
- Speech language pathologists (SLP)
- Occupational therapists (OT)
- Physical therapists (PT)
- Rett syndrome specialist staff (e.g., a neurologist or pediatrician)

At a minimum the team should ideally consist of an SLP, the main caregivers, and the individual with Rett syndrome. However, not everyone may have access to an SLP. Therefore, the term *communication professional* is used in this handbook in preference to SLP. This refers to any professional with expertise (education & experience) in communication and in the assessment and treatment of communication disorders. The communication professional who works with individuals with Rett syndrome is often, but not always, an SLP.

Principles of Teamwork

The team should share a common vision and work collaboratively to define and agree on communication goals and support plans.

Team members should discuss expectations and define each other's roles (e.g., who will be responsible for programming devices or modifying page sets). This should occur at the start of their work and whenever a team member changes.

Principles of Teamwork

One person in the team should be identified as the “key person” with responsibility for monitoring* communication goals.

**Monitoring refers to making sure the therapy plan is being carried out as agreed and alerting the rest of the team when changes are needed.*

The “key person” should be someone who is knowledgeable about Rett syndrome and works with the individual with Rett syndrome regularly. This may be a teacher, teaching assistant, family member, or other person on the team.

Responsibilities of Professionals

Responsibilities of Professionals

Professionals should use an evidence-based practice model to guide their clinical decision-making, incorporating information from the literature, clinical experience, and the wishes of the individual with Rett syndrome and their family.

Professionals should keep their knowledge and understanding of Rett syndrome and AAC up-to-date so that they are aware of recent trends in the literature and in clinical practice. They should also engage with the broader Rett syndrome community and be able to direct caregivers and other communication partners to relevant information and support networks in their community (e.g., through social networks, conferences, websites, and online courses).

Please note, these guidelines are not intended to replace professional codes of conduct, but rather to complement them. This should include any requirements for continuing professional development.

Responsibilities of Professionals

Professionals who are inexperienced in working with individuals with Rett syndrome should seek training in relevant topics, as well as advice and support from colleagues with more specialized knowledge and expertise in this area.

Organizations employing new or inexperienced professionals to work with individuals with Rett syndrome have a duty to enable those professionals to receive training in relevant topics. Professionals should also engage in reflective practice,* with the aim of building their own confidence and knowledge about this area.

**Reflective practice means the ability to analyze one's actions and associated impacts, and to engage in a process of continuous study and self-improvement.*

Responsibilities of Professionals

Professionals who are working in isolation (e.g., working as an independent practitioner) should connect with the other members of the broader team who are working with the individual and family so that support and advice and recommendations are coordinated.

It is the role of the communication professional to:

- train other communication partners in communication techniques and strategies that will benefit the individual with Rett syndrome;
- reinforce training by providing easy-to-read handouts and instructions;
- work with the family and other communication partners to choose the appropriate page sets and/or vocabulary to build into any AAC system or device; and
- work with caregivers/communication partners to problem solve.

Rett Syndrome Specialist Clinics and Expertise Centers

Rett Syndrome Specialist Clinics and Expertise Centers

The individual and family may be referred to a Rett Syndrome Specialist Clinic or Expertise Center in order to get a diagnosis, specialized assessment and advice, or second-opinion at any point following diagnosis.

Some countries and cities have established Rett Syndrome Specialist Clinics or Expertise Centers. Visits to a Rett Specialist Clinic or Expertise Center may be as a single visit or at regular (e.g., annual) intervals. It is unlikely that the Specialist Clinic or Expertise Center will deliver ongoing, day-to-day therapy and intervention.

Communication professionals attached to the Specialist Clinic or Expertise Center should:

- make contact with the locally-treating communication professional(s) to discuss the individual's communication, to share the results of any assessments, and to discuss goals for intervention;
- be available to offer advice and support to, and answer questions from, locally-treating therapists;
- provide training and instruction, and access to resources for locally-treating therapists; and
- be available to respond to questions from parents and caregivers and individuals with Rett syndrome.

Rett Syndrome Specialist Clinics or Expertise Centers may provide consultations and support through video conferencing for individuals who are unable to visit a clinic or center in person (e.g., for individuals living out of the city or country of the Clinic or Center).

