



FIRST 100 DAYS PATHWAY

with Rett syndrome

You are not alone



We know that the diagnosis of Rett syndrome can be overwhelming. You may be confused, scared, frustrated, angry or uncertain, and your emotions may change from day to day, sometimes even hour to hour. We know. We've been there ourselves.

But you are not alone. Become part of Rettsyndrome.org: a network of families, researchers, professionals and volunteers who are determined to make a difference, and are ready to provide you with unbiased and comprehensive information.

We know there is a lot of new language to learn and new systems to navigate. We have created this First 100 Days Pathway to simplify and prioritize this important period of time for you and your family. Contact us directly or visit our website for detailed information and advice about these steps.

While you are adjusting to the diagnosis, it is also a critical window of development for your child, and we want to help all of you get on track as quickly as possible. Keep this handy, and refer to it regularly. Join our social media sites to stay informed. Research is promising. We are working hard for you, and we understand.



THE MISSION of Rettsyndrome.org is to accelerate full spectrum research and empower families with knowledge and connectivity.

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30 Days

FAMILY AND COMMUNITY

- Tell people.
- Surround yourself with supportive, positive people.
- Connect with your own feelings.
- Contact Rettsyndrome.org for support and information.
- Ask a family member or friend to accompany you to all appointments, to help with your child or take notes so you can focus and remember important information.
- Create a personalized Angel Awareness Card and personal webpage through Rettsyndrome.org to simplify educating others and to help raise critical awareness.

MEDICAL

- Organize a binder for yourself of records, tests, contacts (see "Additional Resources")
- Prioritize your child's challenges and focus on these right now.
- Provide Rett specific growth charts to physicians: www.rettsyndrome.org/for-families/media-downloads
- If possible, schedule an assessment at the Rett Syndrome Clinic nearest you www.rettsyndrome.org/for-families/clinics

THERAPY

- What therapy is she currently receiving? Is this what is recommended for a child with Rett syndrome?
- Prioritize your top 3 concerns today and focus on these (for example, Communication, Fine Motor, and Sleep).
- Make a consultation appointment with each of your child's therapists to discuss treatment now that you have a diagnosis. Discuss positioning,

THERAPY CONTINUED

mobility, equipment, feeding, communication, sensory needs and above all make sure the diagnosis opens the horizons of therapeutic potential.

SCHOOL

- Schedule consultation time with your child's Early Interventionist or Classroom Staff to communicate the diagnosis and develop a learning plan emphasizing her potential.
- Turning 3 soon? Research the Individualized Education Plan (IEP) process and begin scheduling evaluations to secure services in school.

INSURANCE AND SERVICES

- Children younger than three receive Early Intervention (EI) services through your State Department of Health.
- Children age 3 and older receive services in school that are secured in the Individualized Education Plan (IEP).
- Review your insurance for which, if any, therapies, tests or out-of-network Rett Clinic assessments are covered to make sure you are getting the most from your providers.
- Document everything.

RESEARCH

- Research which clinicians, specialists and therapists your child needs to see. Talk to other parents for recommendations.
- Educate yourself on current studies.

RECORD

- Start a video record of any unusual behavior to show your physician.
- Track progress or regression.
- Write any changes in your log book.

60 Days

FAMILY AND COMMUNITY

- Talk to your spouse, other children, and family members to connect with their feelings.
- Tell family and friends exactly how they can help. They want to, but don't always know how to ask.
- Connect with other families who are on the same journey as you. Rettsyndrome.org can connect you with families directly or online.

MEDICAL

- Schedule appointments with specialists for baseline evaluations and assessments (neurologic exam, orthopedics, swallow study, EEG, EKG, etc).
- Record any changes in your child. Update your binder.
- Organize new paperwork in your binder. Purge and add as needed.
- Review your calendar for upcoming appointments.

THERAPY

- Schedule a team meeting to review and discuss beneficial therapies specific to Rett syndrome now that everyone has learned more about Rett syndrome.
- Discuss progress towards goals and open lines of communication around setting new goals.

SCHOOL

- Keep an open line of communication.
- Provide educators with research of how children with Rett syndrome learn best.

LEGAL RIGHTS

- Your child might be entitled to services you were not aware of or had not considered
- Research Medicaid Waiver and Federal and State sources of support. There may be wait-lists, don't delay.
- Research Special Needs Wills, Trusts, and ABLE Accounts.

AWARENESS

- Plan or attend a fundraiser or Rett syndrome event in your area.



100 Days

FAMILY AND COMMUNITY

- Research different activities for special needs children.
- Research recreational programs in your area with trained staff that provide inclusive therapeutic, sports and social events for children with special needs.
- Ask family and friends for help with appointments or therapies. They want to help.
- Find a caregiver or sitter for respite.

MEDICAL

- Schedule any remaining tests and appointments, or follow-up appointments.

THERAPY

- Check the progress of your child.
- Communicate any best practices you have learned.

SCHOOL

- Check on your child's progress.
- Communicate any best practices you have learned.

RESEARCH

- Research additional therapy options or specialists, such as therapeutic riding, aquatherapy and more.
- Stay up to date with current research and studies.
- Locate and register for a Rett syndrome conference or webinar.

AWARENESS

- Continue to spread awareness by sharing your child's story.
- Ask your family or friends to help you attend or plan a Rett syndrome fundraiser, awareness or social event in your area.

Next Steps

- Stay in contact with Rettsyndrome.org
- Support comes in many forms, and your needs will change over time
- We will meet you where you are and help you take the next steps



Additional Resources

MAKE AN "ALL ABOUT ME" BOOK

Help others understand Rett syndrome, your child, how Rett syndrome affects your child specifically and how you want them to work with her by creating a simple, personalized "All About Me" book. See website for great examples.

ORGANIZE A BINDER FOR YOU

Three ring binder with tabs including:

- **REPORTS:** Include copies of all diagnostic reports, such as your Rett syndrome genetic diagnosis or EEGs. Ask for an electronic copy of results.
- **PRESCRIPTIONS:** Keep a log of any prescriptions for medications, specialist equipment, therapies or personal care supplies.
- **SPECIALISTS:** Keep a list of all specialists and their contact information or business cards. Specialists include case managers, doctors, therapists, orthotists, educators, equipment vendors, pharmacy, or personal care supply company.
- **THERAPIES:** Include current reports and any handouts for exercises from all therapists, such as PT, OT, SLP, AAC, etc.
- **EQUIPMENT:** Include receipts from equipment vendors, notes on how to use equipment and contact information. Know whom to call if equipment breaks.
- **PROGRAMS:** Include information about the programs or organizations in which your child participates, including Respite care.
- **EARLY INTERVENTION (EI):** Include documents and therapy reports for children under three years old receiving services from the state.
- **INDIVIDUALIZED EDUCATION PLAN (IEP):** Include your child's IEP and any documents related to school for children three and older.

OTHER

Visit the **For Families** section at www.rettsyndrome.org for additional rich and varied resources and information.