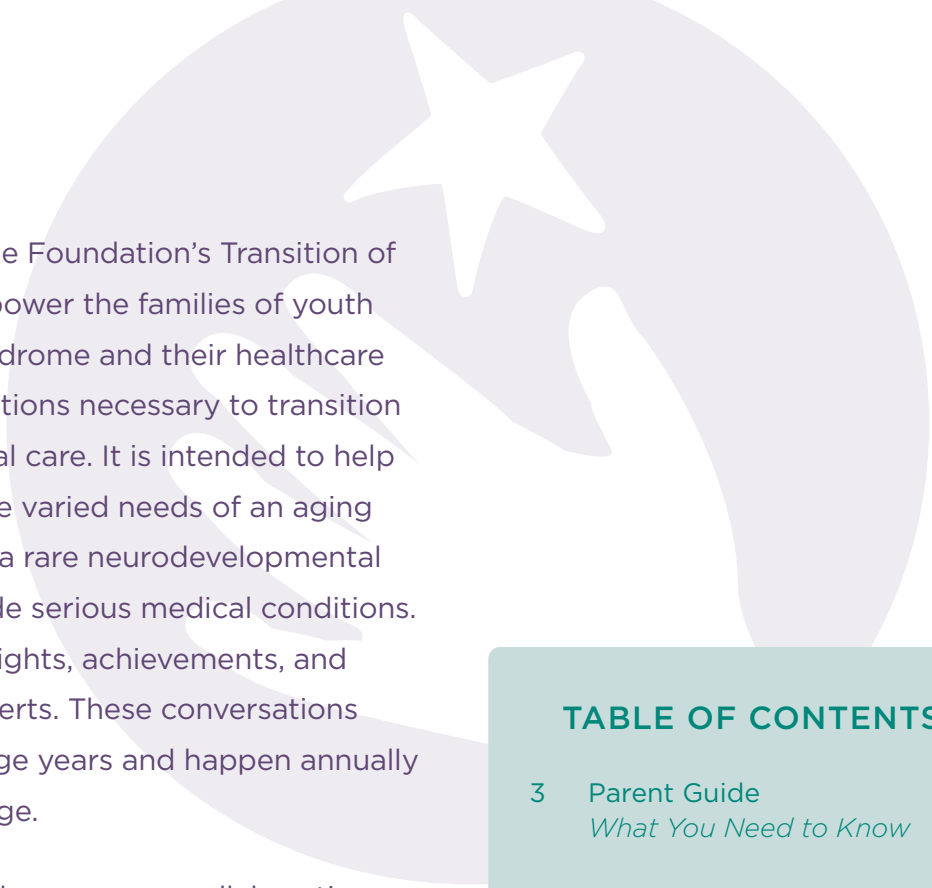




Transition Of Care Toolkit



The International Rett Syndrome Foundation's Transition of Care Toolkit is designed to empower the families of youth and young adults with Rett syndrome and their healthcare providers through the conversations necessary to transition to family-centered adult medical care. It is intended to help Caregivers navigate through the varied needs of an aging loved one with Rett syndrome, a rare neurodevelopmental lifelong disorder that can include serious medical conditions. This toolkit is guided by the insights, achievements, and learnings of caregivers and experts. These conversations should begin in the early teenage years and happen annually as assessments and goals change.

This work is made possible by the generous collaboration of IRSF's 2023 partners in transition of care:

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E-mail info@rettsyndrome.org with questions regarding this toolkit.

Disclaimer: This document is only intended to be a guide for the transition process. It is not intended to substitute medical advice or replace forms that may be required by an individual provider.

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When an individual with Rett syndrome transitions from pediatric to adult care, having a structured plan and process is key, achieved only through a partnership between you, your doctors, and your child. As you begin to develop this plan, keep in mind the following tips, tricks, questions, and “watch-outs” to help you smoothly navigate this process.

WHAT'S DIFFERENT IN ADULT CARE SETTINGS

Advice directly from Rett syndrome parents and caregivers.

Time in the pediatric care system is usually only 20-25 years, but your time in the adult care system can be many more decades. Build relationships and choose care locations accordingly.

- **Locations:** Most adult specialty practices are in private, office-based settings. With pediatric care often located in a hospital, you may be used to more ease of access to labs, imaging, and other services.
- **Multidisciplinary Staffing:** Most pediatric specialty clinics are co-located with other specialists and can offer ancillary therapies. Most adult specialty clinics are not and will need to refer out to other specialists and ancillary therapies.
- **Availability of Care Coordination:** Most pediatric subspecialty clinics and many pediatric primary care practices have care coordination services. There are also several public care coordination programs (e.g., State Title V program) available for youth with specific chronic conditions like Rett syndrome. While many adult primary care practices do have care coordination services, the way you access these services may be different than you are used to. You may need to ask specifically for a care coordinator or social worker to be assigned to assist with care coordination.
- **Medicare:** Know when it happens and how it works with private insurance and Medicaid. Develop your plan and ask your case manager questions well in advance. It takes time to align providers and insurance plans during this transition.

Pediatric versus adult orientation to care, growth, and development are different. Adult care providers may not be thinking about continued growth and development. You may need to advocate for this mindset.

- Encourage new providers to practice a family-centered approach of shared decision-making with parents and caregivers.
- Communicate that your role as caregiver is essential in making appointments, refilling medications, etc.
- When making appointments, request a longer length of appointment time because shorter time is usual in adult settings. You may need extra time for wheelchair transfers, braces removed, diaper changes, etc.
- Offer all new providers reminders and requested workarounds (e.g., no shots or IV medications unless necessary or as necessary if swallowing problems) for adherence to care.



Parent Guide: What You Need to Know

Additional important information:

- Time alone with your child is likely to be expected for at least part of the adult visit. This is legally required for confidentiality for individuals over age 18 unless they give permission for others to be present, or guardianship/conservatorship papers are provided. Make sure to have copies of your legal documents at all visits.
- Providers have the legal option of contacting protective services if needed.
- Medication dosage depends on weight and those with Rett are often small stature.
- The use of pain medications is often more liberally available in pediatrics but may need to be advocated for in adult care environments.

In addition to care that is specific to Rett syndrome, your loved one should receive preventative care and screenings that are recommended for adults by the United States Preventive Services Task Force (USPSTF) or a similar body in your country.

QUESTIONS TO ASK BEFORE TRANSFERRING CARE

Recommended questions to ask your pediatric care provider as you prepare for the transition to adult care.

- Can I work with you to prepare a medical summary and emergency care plan for my child? I have some forms in this Toolkit to assist us.
- Before my child turns 18, what information about privacy, consent, and access to Electronic Health Records (EHR) do we need to learn about, and what actions need to be taken?
- Do you have any suggestions of adult doctors for my child to transfer to?
- What kinds of doctors in adult care does my child need (e.g., a primary care doctor, a specialist, a behavioral health provider)?
- Can you explain the types of specialists who take the lead in the pediatric care world compared to the adult care world? (Examples include who covers tone, pain, sleep, etc.; Will a GP manage a G-tube in the adult world or will a GI? DME?)
- Will you send my child's medical summary to the new adult doctor, and may I also have a copy?
- If needed, will you communicate with the new doctor about my child's care?
- Before the initial visit can be made to the adult doctor, will you still refill their medicines and treat them for acute care needs?
- Can we discuss a planned hospital admission versus an ED situation during the transition at specific ages (18, 21, 22+)? Where do we go and who do we call?
- If you, as a pediatric provider, will continue to see my child after age (18, 22, 25, etc.) but our insurance changes, will we still be able to see you?



Parent Guide: What You Need to Know

QUESTIONS TO ASK YOUR ADULT PROVIDER

Recommended questions for your new provider and reminders for your visits.

- Prior to your first visit, ensure receipt of the transfer package, including final transition readiness assessment, plan of care with transition goals and prioritized actions, medical summary, emergency plan, and if needed, legal documents, condition fact sheet, and additional clinical records.
- Send the [*IRSF Rett Syndrome Primary Care Guidelines*](#) in advance and bring a hard copy to your first visit.
- Consider writing an “About My Child” report so you remember to inform the new provider of things like:
 - Please include and speak to my child, not just me.
 - What mode of communication your loved one with Rett will use to respond, i.e. eye gaze or other technology, and that eye contact, touch, and or vocalizations are other forms of communication.
 - What things need to be in place for your child to feel healthy, safe, and secure at home and in the community.
 - What direct support and monitoring may be needed in the following areas during exams or procedures:
 - Socializing
 - Lifting and/or transferring
 - Healthy and nutritious meals
 - If walking, direct supports to prevent wandering and falling.
 - Scheduling and keeping medical appointments.
 - Taking medications as prescribed.
 - Direct support to manage behaviors and stay regulated.
- Write down a list of questions and concerns you have before seeing your new doctor. These can include:
 - Where do we go if we need to get care after hours or on the weekends?
 - Do you have equipment and testing that is appropriate for adults who are smaller in stature than typical adults?
 - Is there an online portal or app where you can look up your adult loved one’s health information, contact information, or make appointments?
 - When will referrals be required? (A specialist may require a primary care medical referral even if insurance doesn’t. This can mean different things for insurance and for care.)
 - Always ask your doctor to explain information you do not understand.
- When scheduling new appointments, convey “Setting the Stage for Success,” a list of strategies to help ensure appointments, especially the first one, are successful.
 - Ensure all of your paperwork is completed prior to your appointment arrival.
 - Request the first appointment of the day or right after lunch as at these times doctors are less likely to be behind thus decreasing wait.
 - Suggest things that will help regulate your loved one like removing white coats (more common in adult appointments than pediatrics).



Parent Guide: What You Need to Know

- Request one room to have all activities done if possible (i.e., intake, scheduling appointments, etc.).
- Allow for flexibility for your individual's needs (walking around a room, etc.).
- Have a crisis plan.
- Keep a record of your adult child's medical history, current medications, including how much they take, how often, and why, allergies to medicines, and vaccine history. You can take a picture of your medicine label and bring it with you to your visit or use the *My Rett Ally* web app to keep your list.
- Keep your doctor's phone number in your phone or somewhere you can easily find it.
- Keep your child's health insurance card with you always.



Master Provider Summary

Patient Name: _____

Date of Birth: _____

Primary Caregiver Name: _____

Last Updated: _____

SPECIALTY	CURRENT PEDIATRIC PROVIDER	ADULT PROVIDER/ TRANSITION PLAN
Example: Primary Care Provider	Dr. John Doe Rett Syndrome Clinic (2023 Pediatric Road, Anytown, State 12345) (123) 456-7890 Within current Children's Hospital	Dr. Jane Doe Rett Syndrome Clinic (2023 Adult Road, Anytown, State 12345) (123) 456-7890 Within Adult Hospital recommended to follow the individual Hospital <i>Pediatrician, exact age of transfer unclear currently. Would likely benefit from a MedPeds provider long term.</i>
Primary Care Provider (PCP)		
Emergency Admission		
Complex Care/Transition Provider		
Neurology (epilepsy, movement, sleep)		
Gastroenterology		
Dietitian/Nutrition		
PMR/Physical Rehab		
Orthopedics: spine/hips		



Master Provider Summary

SPECIALTY	CURRENT PEDIATRIC PROVIDER	ADULT PROVIDER/ TRANSITION PLAN
Pulmonology/Sleep		
Cardiology		
Endocrinology		
Other		
MyChart, EPIC, KP.org or other Electronic Health Record System(s)		
OUTSIDE FACILITIES		
Communication/AAC		
Dental		
Ophthalmology		
Psychiatry		
Other		



Transitions Checklist

YOUNG ADULT WITH RETT SYNDROME

Patient Name: _____ Date of Birth: _____

Pertinent active diagnoses (list all):

Prioritized list for the individual with Rett syndrome + active problems for this individual (epilepsy, behavior, constipation, sleep, etc.)

Inactive or currently resolved diagnoses (*i.e., kidney stones, central apnea, epilepsy, pneumonias, etc.*)

TRANSFER OF CARE TRANSITION MASTER CHECKLIST

Comprehensive transfer package to include:

- Comprehensive transfer letter, including effective date of transfer of care to adult provider.
- Self-care assessment, completed by caregiver with patient, as appropriate.
- Plan of care, including goals and actions.
- Updated medical summary and emergency care plan. Bring a copy even if the office has its own form. Complete in advance to make most of appointment time.
- Legal documents.
- Condition fact sheet.
- Updated medical summary and emergency care plan. Bring a copy even if the office has its own form. Complete in advance to make most of appointment time.
- Immunizations. Sent on Date: _____
- Communicated with adult provider about transfer. Date: _____
- Elicited feedback from caregiver and young adult after transfer from pediatric care. Date: _____

Additional comments/notes: _____



Transitions Checklist

SPECIALTY: _____

Request each relevant specialty provider (i.e. pediatrician, neurology, gastroenterology, etc.) to complete and utilize this Checklist for duration of the transition period

Patient Name: _____ Date of Birth: _____

Primary Diagnosis: _____

Transition Complexity (low, moderate, or high): _____

TRANSITION POLICY

Practice policy on transition discussed/shared with youth and parent/caregivers. Recommended revisiting at multiple young adult visits.

Date: _____ Date: _____ Date: _____

Included transition goals and prioritized actions in plan of care.

Date: _____ Date: _____ Date: _____

MEDICAL SUMMARY AND EMERGENCY PLAN

Updated and shared medical summary and emergency plan.

Date: _____ Date: _____ Date: _____

FAMILY-CENTERED ADULT MODEL OF CARE

Decision-making, privacy, and consent in family-centered adult care discussed with youth and parent/caregiver. If appropriate, discuss plans for supported decision-making and HCBS. Date: _____

The timing of transfer discussed with youth and parent/caregiver. Date: _____

Adult provider selected. Date: _____

Provider Name & Contact Information: _____

First appointment scheduled for: _____ First appointment completed on: _____



Self-Care Assessment

Instructions

This document should be completed by the parents and/or caregivers along with the youth/young adult with Rett syndrome. Indicate if the current goals are new or ongoing, what has been tried previously, and if things have improved or gotten worse over time/since diagnosis. It is ideal if your new physician establishes a baseline assessment and reviews medications, treatments, and testing if needed. Parents/caregivers should encourage a discussion about any differences in the model of care for a particular discipline between pediatrics and adult providers.

Intent

This document will help us see what you and your youth/young adult already know about their health and will help us find areas that you think they (or you) need to know more about.

Today's Date: _____

Patient Name: _____ Date of Birth: _____

Primary Diagnosis: _____ Caregiver Name: _____

Relationship to Patient: _____ Are you the main caregiver? Y I N

DECISION-MAKING/GUARDIANSHIP

- My young adult needs help with making health care choices.
- My young adult has a legal guardian. Name: _____
- We need a referral to community services for legal help with health care decisions, guardianship and conservatorship.

PERSONAL CARE

- My young adult can care for their own needs with help.
- My young adult requires help for all their needs.

TRANSITION AND SELF-CARE IMPORTANCE

How **confident** do you feel about **your** ability to take care of **your loved one's** health care?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1 Not Confident	2 Somewhat Unconfident	3 Neither Confident or Unconfident	4 Somewhat Confident	5 Very Confident



Self-Care Assessment

UNDERSTANDING YOUNG ADULT'S HEALTH

Please check the box that applies to you right now. Note that “We” refers to the primary parents/caregiver and the individual with Rett syndrome.

	Yes we know this	We need to learn this and they need full assistance
We know their medical needs.	<input type="checkbox"/>	<input type="checkbox"/>
We can tell other people what their medical needs are.	<input type="checkbox"/>	<input type="checkbox"/>
We know what to do if they have a medical emergency.	<input type="checkbox"/>	<input type="checkbox"/>
We have an emergency care plan documented. <i>Make sure to share this plan with your provider.</i>	<input type="checkbox"/>	<input type="checkbox"/>
We know the medicines they take and what they are for.	<input type="checkbox"/>	<input type="checkbox"/>
We know what they are allergic to, including medicines.	<input type="checkbox"/>	<input type="checkbox"/>
We can name 2-3 people who can help them with their health goals.	<input type="checkbox"/>	<input type="checkbox"/>
We have documented 2-3 people who can help them with their health goals.	<input type="checkbox"/>	<input type="checkbox"/>



Self-Care Assessment

USING HEALTH CARE

Please check the box that applies to you right now. Note that “We” refers to the primary parents/caregiver and the individual with Rett syndrome.

	Yes we know this	We need to learn this and they need full assistance
We and 2-3 people know or can find their doctor’s phone number.	<input type="checkbox"/>	<input type="checkbox"/>
Before a visit, we think about questions to ask.	<input type="checkbox"/>	<input type="checkbox"/>
We have a way to get to their doctor’s office.	<input type="checkbox"/>	<input type="checkbox"/>
We know to show up 15 minutes before the visit to check in.	<input type="checkbox"/>	<input type="checkbox"/>
We know where to get care when their doctor’s office is closed.	<input type="checkbox"/>	<input type="checkbox"/>
My young adult, myself and 2-3 others have a folder or access to My Rett Ally with their medical information, including medical summary and emergency care plan.	<input type="checkbox"/>	<input type="checkbox"/>
My young adult, myself and 2-3 other people have a copy of their plan of care.	<input type="checkbox"/>	<input type="checkbox"/>
We know how to ask for a form to be seen by another doctor/therapist (i.e., referral).	<input type="checkbox"/>	<input type="checkbox"/>
We know where their pharmacy is and what to do if they run out of medicines.	<input type="checkbox"/>	<input type="checkbox"/>
We know where to get a blood test or x-rays if the doctor orders them.	<input type="checkbox"/>	<input type="checkbox"/>
My young adult, myself and 2-3 others have health information with them every day (e.g., insurance card, allergies, medications, and emergency phone numbers).	<input type="checkbox"/>	<input type="checkbox"/>
We have a plan so they can keep their health insurance after 18 or older.	<input type="checkbox"/>	<input type="checkbox"/>

Self-Care Assessment

Please include here any other concerns or thoughts you wish to share with your health care team regarding the health of your young adult, such as:

- Pain tolerance
- Supervision requirements (like a sitter at bedside or translator for nonverbal person)
- Not safe in bed without padding for guard rails for entrapment risk
- Needs extra time to regulate to an unfamiliar environment
- Better during exams if favorite music or movie playing

YOUNG ADULT WITH RETT SYNDROME

Instructions

This document should be completed by medical providers in collaboration with primary caregiver and young adult.

Intent

This document should be shared with the transitioning patient's new medical providers, as well as the patient himself/herself and his/her caregivers, as appropriate.

PATIENT INFORMATION

Patient Name:

Date Form First Completed:

Date/s Form Revised:

Form Completed by:

PRINCIPAL TRANSITION MEDICAL PROVIDER'S CONTACT INFORMATION

Name:

Address:

Work Number:

Best Time to Reach:

Email:

Best Way to Reach: Phone Email

TRANSITIONING PATIENT CONTACT AND INSURANCE INFORMATION

Name:

Nickname:

DOB:

Preferred Language:

Address:

Cell #:

Home #:

Best Time to Reach:

Email:

Best Way to Reach: Text Phone Email

Health Insurance Plan:

Group and ID

Limited Legal Status? Y N

Tutorship Y N

Guardianship Y N

*****Legal documents to be provided by parents or primary caregivers** Please attach.***



Medical Summary

SCHOOL AND COMMUNITY PROGRAM INFORMATION

Agency/School	Contact Person	Phone/Fax	Email

EMERGENCY CARE PLAN

Name:		Relationship to Patient:
Phone (Cell):	Phone (Other):	Email:

Preferred Emergency Care Location:

Special precautions (e.g., seizure action plan, allergies, medications that cannot be missed, DME that is needed at all times, etc.):

ETIOLOGY (CHECK ALL THAT APPLY; DESCRIBE)

<input type="checkbox"/> Genetic/Chromosomal	<input type="checkbox"/> Prenatal Substance Exposure	<input type="checkbox"/> Prenatal Viral Exposure
<input type="checkbox"/> Preterm Birth	<input type="checkbox"/> Infection	<input type="checkbox"/> Acquired (e.g., TBI, Submersion injury)
<input type="checkbox"/> Metabolic	<input type="checkbox"/> Other (specify)	<input type="checkbox"/> Other (specify)
<input type="checkbox"/> Unknown (specify)		



Medical Summary

DIAGNOSES AND CURRENT PROBLEM

Primary

Problem (List)	Details and Recommendations

Secondary Diagnoses

Problem (List)	Details and Recommendations

Associated Behavioral Issues

Please specify:

Allergies	Reactions
Avoid	Why?
Medications (List)	
Medical Procedures (List)	

CURRENT MEDICATIONS

Medications	Dose	Frequency	Medications (Con't)	Dose	Frequency
1.			7.		
2.			8.		
3.			9.		
4.			10.		
5.			11.		
6.			12.		



Medical Summary

PRIOR MEDICATIONS FOR COMPLEX MEDICATION HISTORIES (E.G., EPILEPSY)

Medication	Duration	Reason Discontinued & Comments

PRIOR SURGERIES, PROCEDURES, HOSPITALIZATIONS AND WHY (INCLUDE IMAGERY WHERE AVAILABLE)

Date:	
Date:	
Date:	
Date:	
Date:	
Date:	
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Date:	
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Date:	
Date:	



Medical Summary

ADAPTIVE FUNCTIONING DOMAINS (CURRENT ACTIVITIES)

Communication	<i>Example: Verbal? Nonverbal? Vocal but nonspeaking? AAC User with what symbol system or device(s)?</i>		
Social			
Nutritional Issues			
Sleep Issues			
Mobility	Independent?	Aides?	Wheelchair?
	Other?		
Self-Care			
Leisure			
Work			
Community Activities			
Safety Issues			
Additional Information	<i>Example: Receptive much higher than expressive; requires time to acclimate to new environments/people, becomes disregulated when hungry</i>		
Best learning method	<i>Example: Written pamphlet, diagrams, anatomical doll, etc. (adult version of Child Life Specialist?)</i>		
Best Yes/No	<i>Example: Touch screen iPad, PECS cards, eye gaze device, specific body language like turning away for No, or raising eyebrows for Yes</i>		



Medical Summary

EQUIPMENT, APPLIANCES, AND ASSISTIVE TECHNOLOGY (CHECK ALL THAT APPLY)

<input type="checkbox"/> Gastrostomy	<input type="checkbox"/> Communication Device	<input checked="" type="checkbox"/> Monitors	Other:
<input type="checkbox"/> Tracheostomy	<input type="checkbox"/> Wheelchair	<input type="checkbox"/> Apnea	
<input type="checkbox"/> Suctions	<input type="checkbox"/> Orthotics	<input type="checkbox"/> Cardiac	
<input type="checkbox"/> Nebulizer	<input type="checkbox"/> Cough Assist	<input type="checkbox"/> Oxygen	
<input type="checkbox"/> Adaptive Seating	<input type="checkbox"/> Walker	<input type="checkbox"/> Glucose	

ADDITIONAL NOTES OR INFORMATION NOT COVERED ABOVE
