

PLANNING OPPORTUNITIES FOR UPTIME

Follow these 4 steps to create and implement a daily routine of "uptime" activities for and with the person with Rett syndrome.

Step 1. Assess what activities could be possible?

Assess your individual situation. Talk with family members, therapists, and support workers, and the person with Rett syndrome.

Write down the answers to the following:

1. What are the person's motor skills?
 - a. Can the person stand or walk on their own or do they need help?
 - b. How long can they stand or walk for?
 - c. How long does the person sit? You may consider planning breaks for movement during long periods of sitting.

Motor skills:

2. What are the person's interests?

- a. Are there activities or tasks that they particularly like? For example, do they like being with people or outdoors?
- b. Are there activities that can provide responsibility for the person with Rett syndrome in household tasks?

Interests:

3. What are your usual schedules and activities?

- a. Think about routines when getting up in the morning, after school and when going to bed in the evening for "uptime" opportunities.
- b. Think about activities with siblings, friends, neighbours, etc.

Usual schedules and activities:

4. Who are your available support persons for regular "uptime" activities?

- a. Who in your family can support the person's "uptime" routines?
- b. Are there persons at school or activity centres who can support "uptime" routines?
- c. Are there other carers who can support "uptime" routines?

Available support persons:

5. What special equipment could help?

- a. Do you have the equipment that you need?
- b. People with Rett syndrome may use a standing frame, a walker or switches to help with activities [[hyperlink to our equipment page](#)]

Equipment:

Now, make a list of what "uptime" activities could be practiced, where and when, who with, and whether new equipment is needed.

Uptime Activity 1:

Uptime Activity 2:

Uptime Activity 3:

Uptime Activity 4:

Uptime Activity 5:

Uptime Activity 6:

Step 2 Understand why the "uptime" activities are important for the person

Standing and walking activities are important for good health, mental health and quality of life. Standing and walking activities can help in many ways:

1. Developing and maintaining balance, muscle coordination, fitness, and strength.
2. Better motor skills for safer movements.
3. Practising tasks for independence.
4. Opportunities for choice and control.
5. Self-regulation - walking can be calming.

Make of list of why the "uptime" activities are important for your person with Rett syndrome.

<input type="checkbox"/> Developing and maintaining balance. <input type="checkbox"/> Developing and maintaining muscle coordination. <input type="checkbox"/> Developing and maintaining fitness. <input type="checkbox"/> Developing and maintaining strength. <input type="checkbox"/> Better motor skills for safer movements. <input type="checkbox"/> Practising tasks for independence. <input type="checkbox"/> Opportunities for choice and control. <input type="checkbox"/> Self-regulation. <input type="checkbox"/> Other _____ <input type="checkbox"/> Other _____ <input type="checkbox"/> Other _____
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Step 3 Set your goals

Set your goals. You can have 1 to 3 goals at a time. The goal should include:

- **What** activity you decide to do;
- **Where** to do the activity;
- **When** to do the activity;
- **Who** to do the activity with; and
- **Why** do the activity (from Step 2)

Goal 1:

Goal 2:

Goal 3:

Step 4 Make your routine of regular "uptime" activities

	Sun	Mon	Tues	Wed	Thurs	Fri	Sat
Morning							
Afternoon							
Evening							