## 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, during the day, after school or activity centre, 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, in your home or in your community who can support uptime routines?
  - c. Are there other carers or people in your life who can support uptime routines?

Available support persons:

- 5. What 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:

## <u>Step 2 Understand why the uptime activities are important for the person</u>

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.

| Developing and maintaining balance.                       |
|---|
| $\square$ Developing and maintaining muscle coordination. |
| $\Box$ Developing and maintaining fitness.                |
| $\Box$ Developing and maintaining strength.               |
| $\Box$ Better motor skills for safer movements.           |
| $\Box$ Practising tasks for independence.                 |
| $\Box$ Opportunities for choice and control.              |
| $\Box$ Self-regulation.                                   |
| □ Other   |
| □ Other   |
| □ Other   |

## <u>Step 3 Set your goals</u>

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:

|           | Sun | Mon | Tues | Wed | Thurs | Fri | Sat |
|-----------|-----|-----|------|-----|-------|-----|-----|
| Morning   |     |     |      |     |       |     |     |
| Afternoon |     |     |      |     |       |     |     |
| Evening   |     |     |      |     |       |     |     |

| Step 4 Make your routine of regular uptime activities |
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