

'Uptime' - activities in standing and walking



115

parent caregivers and



49

therapists from



28

countries

gave us their top tips for how to support 'uptime' in Rett syndrome. See what they told us.

SUPPORT FOR THE PERSON

Fitness and function - building physical capacity

- Embed 'uptime' in everyday routines
- Allow time for activities to start and then be completed
- Look for signs that activities are manageable and enjoyable
- Include breaks within the activity to achieve more activity without fatigue
- Create breaks for movement within long periods of sitting

Fun activities - individual interests

- Explore opportunities for enjoyment, social engagement and learning
- Consider activities that offer responsibility (e.g., household chores, grocery shopping)
- Work towards self-chosen activities that are motivating
- Give praise for achievements and rewards according to individual preferences

Family and friends - a rich social environment

Create a supportive team of helpers

- Plan together with the individual, families and helpers
- Combine 'uptime' and social activities with family, classmates and within community environments
- Focus on the activity rather than performance

Opportunities in the physical environment

- Be active in different environments - in indoor and outdoor settings, at home, at school and in the community
- Explore natural environments
- Use adaptive equipment where appropriate at home and school
- Consider adjustments to furniture, e.g., standing stations in the house

SUPPORTIVE ENVIRONMENTS

'Uptime' is important for health and wellbeing. We hope you enjoy designing new routines and activities to increase 'uptime' for individuals with Rett syndrome.

For further information, please contact Associate Professor Jenny Downs at jenny.downs@telethonkids.org.au