

When you build routines into your day to increase uptime, it doesn't only affect the person with Rett syndrome; it affects the whole family.

Especially, it affects their caregivers, because caregivers plan and often carry out the activities with their daughters or sons.



"My daughter cannot initiate any active movements so if there is any increase in movement it has to be done by the staff or myself."



If you're a caregiver, you spend a lot of time thinking about your child. Now take a few minutes to consider your own health and wellbeing: how you are going physically, mentally and socially. That's important because it affects your child and the rest of your family.

## Here are some tips from other caregivers:

- Take time out for yourself; maintain your interests.
- Don't ignore your own health problems.
- Don't try to do everything: Choose which activities you want to do with your child and which activities you want to hand over others.
- Practice mindfulness.
- Take breaks.
- Get regular exercise.
- Maintain your social contacts.
- Live all your roles, not just your caregiver role.
- Make use of available supports.
- Advocating for your child with organizations can be stressful. So pick your battles: Choose which issues you are prepared to fight for and which you are prepared to let go.
- Many caregivers worry about their child's future: Talk about the issues with your family and plan ahead.
- Get involved with support groups (such as your Rett syndrome Association) and with local non-disability groups (such as your local footy club, your church, your family), whatever works for you.

