

Fact Sheet

Back Care for Parents and Carers of Children with Rett Syndrome



Looking after your back

The majority of carers of children with Rett syndrome experience some back pain. The daily care of children with Rett syndrome is physically demanding because these children:

- may not reliably respond to, or comply with instructions;
- cannot use their hands and/or arms to assist with lifting;
- have difficulty transferring from one position to the other (eg lying to sitting or standing, moving up the bed);
- need life long help with all activities of daily living including, bathing, dressing and toileting;
- may have problems with altered muscle tone that may affect the way they need to be lifted or positioned;
- may have unexpected changes in their level of mobility due to pain, surgery or a fracture;
- need constant supervision and assistance

Looking after your back is a complex issue

- In addition to caring for your child you use your back when doing household chores, shopping, employment and recreational activities.
- When children are young and need our help we lift them frequently. It can be difficult to recognise when the care we are giving to children who are not gaining independence has gone beyond what can be safely expected.
- All parents want their children to grow and develop normally, so may feel reluctant to start using special equipment such as a hoist, which acknowledges a child's disability.

- It is often difficult to ask for help. It is natural to want to retain your family's privacy and independence. It is reasonable to want your house to feel like a normal family home, not like a hospital.
- Equipment is expensive and takes up space. Initially it may seem to make care slower and more difficult.

It is important to think carefully about the future – rather than waiting for a crisis to occur

- Homecare workers have occupational health and safety standards. They are not permitted to lift a person over 16kgs unless using special manual handling equipment, such as an electric high/low bed, a hoist or a shower chair.
- If you do not have manual handling equipment it may take some time (months or years) to get the right assessments and funding.
- An injury or problem with your back will make caring for your child very difficult without manual handling equipment.

Assess your physical risk factors

- Is your child over 16kg?
- Do you lift your child frequently?
- Do you bend or twist when lifting?
- Do you sometimes lift in a restricted space?
- Is your child awkward to lift?
- Is it awkward to keep your child close to your body while lifting them?
- Do you lift your child from a low height or surfaces above waist height?

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- Do you often need to reach or bend forward?
- Is it hard to get help to lift when you need it?
- Do you experience back pain?
- Have you previously needed treatment for a back injury or back pain?
- Do you have any arm or leg pain or injuries?

If you answer **yes** to any of these questions you are at risk of a back injury.

What you can do

Gather information

- Assess your situation – write down exactly what you do in a day/week so that you can gain a clearer picture of when and how often you are lifting. This may help you find ways of eliminating lifting, or changing the timing of activities so that you can get more help.
- Talk to other parents of children with Rett syndrome or visit the IRS web site <http://www.rettsyndrome.org/>
- Search the internet and research different types of equipment to discuss with your therapy team.
- Request help from an Occupational Therapist as soon as possible. There can be a waiting time for services and funding may be limited. An Occupational Therapist can advise and assist with applications for equipment and home modifications.

Implement Back Care Strategies

– during all lifting activities

- Consider technique:
 - Plan your lift or transfer.
 - Make sure obstacles are out of the way.

- Lift with your child's weight, or any other object you are lifting, close to your body.
 - Use your legs to do the work; do not bend your back.
 - Tighten your stomach muscles without holding your breath - this provides your back with extra support during the activity.
 - Ask for assistance if the task is too heavy or awkward.
 - Avoid lifting above your head or below your knees.
 - Consider enrolling in a manual handling course or ask your therapy team for specific manual handling advice. The appendix has some extra ideas to help you care for your back.
- Consider obtaining manual handling equipment such as:
 - Slide sheets (moving child up the bed, pivoting into car).
 - Pivot pads for transfers.
 - Hoists.
 - Electric high / low beds – lowered for independent transfers or raised to provide a better working height for changing and dressing etc.
 - Wheelchairs.
 - Mobile shower/toilet chairs.
 - Plan for the future when purchasing a house or a car. For example you may need:
 - To consider the number of stairs and steps.
 - Space and a flat floor to allow for shower equipment.
 - Space to allow the use of a hoist.
 - A modified van, for example with a lifting platform, to transport your child in a wheelchair.

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- When buying a new wheelchair check its suitability for transporting your child in a vehicle. Even if you don't have a modified vehicle, your child may need it if they are to be transported to school in a taxi.
- Take care of yourself
 - Try a regular exercise routine, even just a 20 minute walk every few days, will keep your muscles in good condition and make caring for your child safer and easier.
 - Seek treatment and advice at the first sign of back pain
 - Ask yourself, would you expect someone else to do what you are doing?

Remember

- Many parents suffer back pain and injuries when caring for their children with a physical disability.
- A back injury can make it difficult to care for your family and will affect your quality of life.
- You can do something now and in the future to stop an injury occurring.

This fact sheet is for education purposes only.
Please consult with your doctor or other health professional
to make sure this information is right for your child.

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