

### Contact details

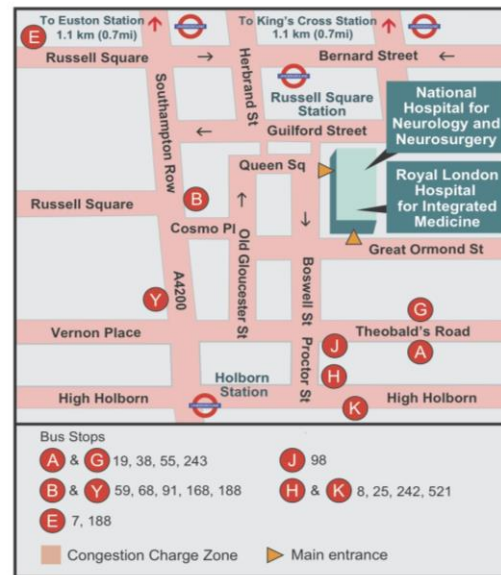
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The Clinical Specialist Physiotherapist is available from 9.00am to 5.00pm Monday to Friday (excluding bank holidays).

### Where can I get more information?

Muscular Dystrophy UK

If you need a large print, audio or a translated copy of this document, please contact the nurse specialist directly. We will try our best to meet your needs.



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## National Hospital for Neurology and Neurosurgery

Pacing, grading and Energy conservation ideas for patients with Channelopathy

Centre for Neuromuscular Diseases

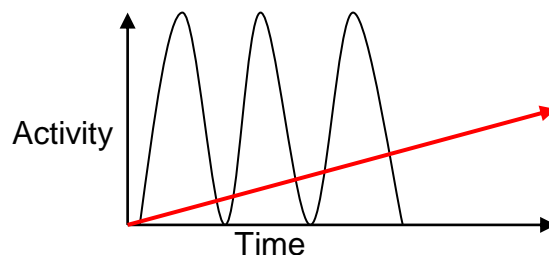
This leaflet has been written by the Specialist Physiotherapist who works for the muscle channel service. The leaflet provides information about fatigue, and ideas about how people with Channel disease can help to manage their fatigue. The leaflet is for people seen at the Channel clinic at the National Hospital for Neurology and Neurosurgery. Patient's family or carers may also find this information helpful.

## Fatigue and muscle ion channelopathy

Each person with channel disease will experience a different pattern of triggers for their symptoms. Exercise, and/or cold can be triggers. Symptoms vary person to person, even within the same diagnosis. Some people experience an episode of paralysis when they rest, after exercising. Other people experience weakness during exercise, or after strenuous exercise, and some feel stiffness after sudden movements. People often avoid exercise and reduce what they do. Being less active causes muscles to become weak and your body to become deconditioned. This can mean that you feel tired when you start to do a bit more.

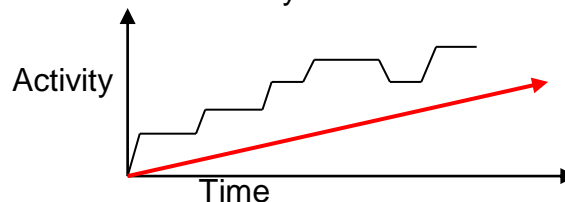
## Ideas and suggestions to help manage fatigue

Planning to increase your activity levels, and to be more active in the day are ways that you can start to strengthen your muscles and improve your overall fitness and energy levels. It is important that you try to avoid going from doing nothing to doing lots and lots, and needing to rest for days to recover. This is called the “boom-bust” activity cycle.



**Planning** small amounts of **activity and rests**, and aiming to very gradually increase what you do over weeks and months can help you to optimise your activity levels without negatively impacting on your fatigue.

This graded approach, can help your body to gradually adapt to doing more, and should mean that you don't need to rest for days to recover from activity.



## Key principles for helping gradually increase activity

### Plan ahead

Make a weekly timetable of the activities you want to and need to do. Try to:

- Plan to **rest when your energy levels are low**
- **Do not exercise to the point of exhaustion**
- Aim to focus on doing what you can each time you are active
- Plan some time to rest or relax after activity
- Plan activity with rest days between
- Think about trying to maintain **good quality activity** or exercise, not working into fatigue and noticing any changes or signs that you might be close to triggering your symptoms
- Try to incorporate **small bouts of activity**, planning to gradually increase the amount of good quality activity you are able to do without triggering your symptoms
- Plan to gradually increase what you are doing over weeks or months

**Sleep well, eat well and keep active –** the physiotherapist in clinic will be able to support you to think about exercising, to optimise your strength and fitness.