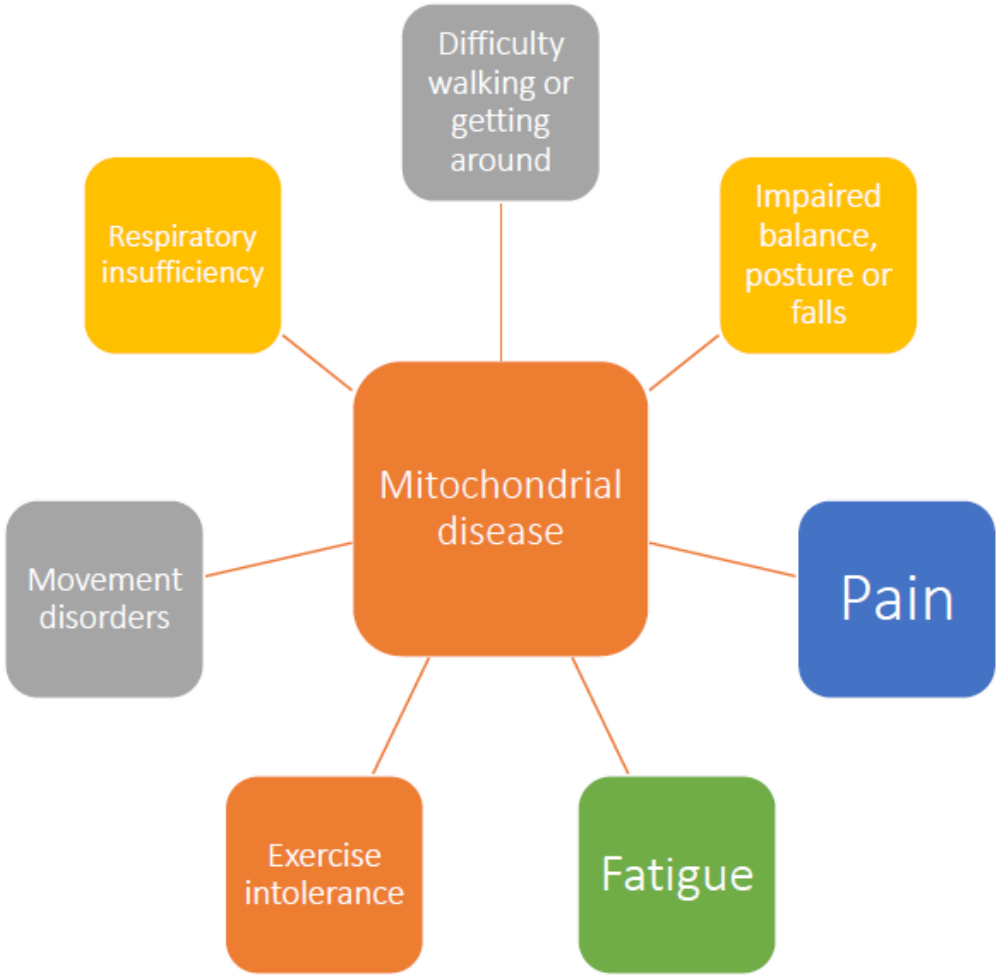
Fatigue management and exercise for people with mitochondrial diseases

Sarah Holmes
Clinical Specialist Physiotherapist
HSS Mitochondrial Disease Service
National Hospital for Neurology and Neurosurgery

Session aims

- Mitochondrial disease – everyone is different
- Fatigue – definitions and possible causes
- Strategies to help manage fatigue
- Considerations for exercise
- Exercise advice
- Your top tips

Common physical challenges for people with mitochondrial disease



What is fatigue?

‘ A subjective lack of physical and /or mental energy that is perceived by the individual or caregiver to interfere with usual and desired activity.’

- Different from tiredness
- Mental and/or physical fatigue
- Varies person to person
- Not always helped by rest
- Daily variations and fluctuations
- Invisible, mis-understood and difficult to describe


Disease process
Pain
Mood
Fitness
Fatigue
Medication
Environment
Infection
Sleep

Understanding your fatigue

- Is my sleep disturbed?
- Do my medications contribute to fatigue?
- Am I taking any exercise?
- How much is my mood affecting my fatigue?
- How does my fatigue fluctuate during the day?
- Do I feel better after a rest?

Individual and varied experience

- Identify patterns and triggers
- through fatigue diary and
- energy conservation scale

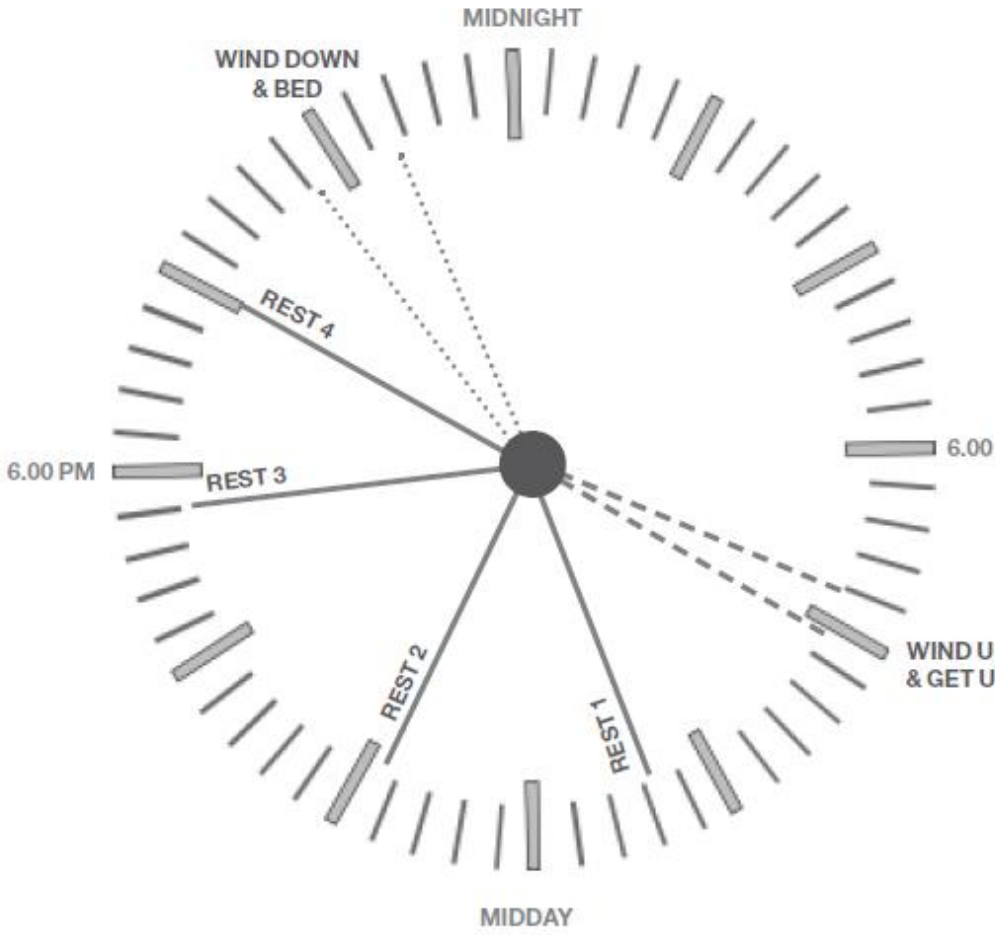
	LOW (NOT TIRING)	MEDIUM (MODERATELY TIRING)	HIGH (VERY TIRING)
	Listening to the radio Watching TV	Driving to work Surfing the net Playing on the Nintendo Wii Talking on the phone Reading the newspaper	Socialising in the evening Gardening
	Light housework Brushing teeth Making a cup of tea	Making dinner Getting showered Attending meetings Walking up stairs Getting dressed	
		Washing the car	Mowing the lawn Going supermarket shopping Doing the ironing Vacuuming

Energy conservation techniques

- Pacing activity
- Breaking tasks into stages
- Planning rests
- Prioritising and delegating
- Sleep and eat well
- Rest breaks without stimulation
- Ergonomics

Rests and relaxation

- Take regular rests
- Aim for no stimulation/TV
- Relaxation or meditation
- Relaxing music
- 10-20 minutes to recharge batteries



Considerations for exercise

Fatigue

- need enough energy to get washed, dressed and do the things you really need to do each day

Safety

- Heart involvement - talk to the team
- Risk of falls

Enjoyment and variety

- Moving about, or avoiding sitting still for too long as important as exercise
- Different exercises, eg vestibular rehab if have balance problems

Talk to the team, or arrange to see Physio if you have any questions about exercise

- Shouldn't feel pain >48 hrs
- Don't exercise to the point of exhaustion
- Avoid stopping or staring without warm up/down or stretch

Muscular Dystrophy UK
Fighting muscle-wasting conditions

Exercise advice for adults with muscle-wasting conditions

TYPE OF EXERCISE	FREQUENCY	INTENSITY	DURATION	PRECAUTIONS
Aerobic exercise *E.g. walking to work, wheeling your wheelchair, activities of daily living, cycling, swimming or static bike* Any activity that uses large muscle groups and can be maintained continuously and rhythmically for a period of time	Try and make being active part of your daily routine or try to be active in these ways at least five times a week	Comfortably out of breath but still able to talk Borg scale 3 to 5	30 minutes, or intermittent bouts aiming for at least 10 minutes	Do not exercise to exhaustion
Strengthening exercises *E.g. exercise bands, small weights or Pilates* Individual programme: seek advice about which muscles you should strengthen	Two to three times a week	Stop before fatigue	One set of 8 to12 repetitions for each muscle group identified	Low to moderate weights Increase number of repetitions rather than weight
Flexibility *E.g. stretches (seated or standing), yoga* Static or passive stretch	Try to do this as part of your daily routine or at least Two to three times a week	Stretching sensation but not pain*	30 to 60 seconds Two to four times	Do not 'bounce' No pain

***Take extra care with any of the above if you have altered sensation, very weak muscles or poor balance.**

Borg Scale of Perceived Exertion

0	Nothing at all
1	Very light
2	Fairly light
3	Moderate
4	Somewhat hard
5	Hard
6	
7	Very hard
8	
9	
10	Very, very hard

Aim to work at 3-5

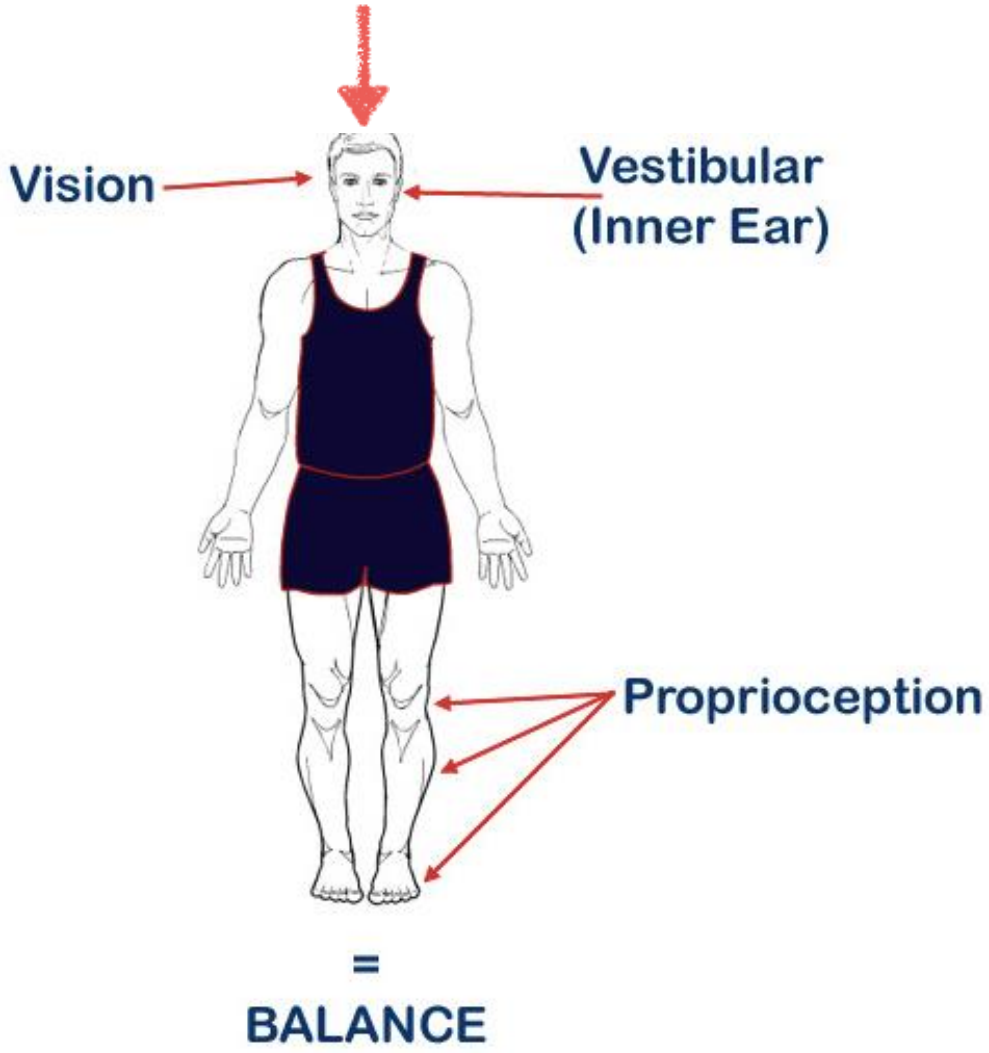
Borg RPE scale © Gunnar Borg, 1970, 1985, 1994, 1998

A little warmer, deeper breaths, start to sweat a little

still able to comfortably talk in full sentences

Balance

Central control of movement and co-ordination



http://virinchihospitals.com/livehealthy/wp-content/uploads/2015/09/images/components.jpg

Good evidence of benefits of Vestibular rehabilitation

Vestibular rehabilitation for unilateral peripheral vestibular dysfunction (Review)

Hillier SL, McDonnell M

Journal of Neurologic Physical Therapy. 40(2):124–155, APR 2016
DOI: 10.1097/NPT.0000000000000120, PMID: 26913496
Issn Print: 1557-0576
Publication Date: 2016/04/01

Print

Vestibular Rehabilitation for Peripheral Vestibular Hypofunction: An Evidence-Based Clinical Practice GuidelineFROM THE AMERICAN PHYSICAL THERAPY ASSOCIATION NEUROLOGY SECTION

Courtney Hall;Susan Herdman;Susan Whitney;Stephen Cass;Richard Clendaniel;Terry Fife;Joseph Furman;Thomas S. Getchius;Joel Goebel;Neil Shepard;Sheelah Woodhouse;

Benign paroxysmal positioning vertigo in multiple sclerosis: diagnosis, pathophysiology and therapeutic techniques

E M Frohman, P D Kramer, R B Dewey, more...

First Published June 1, 2003 | Research Article
https://doi.org/10.1191/1352458503ms901oa

Your top tips