

Scottish Muscle Network

Patient Information Leaflet

Fatigue management in muscle disorders

Introduction

This leaflet helps to explain fatigue (also known as Fatigue Management) and give you some ideas on how to help you cope.

What is fatigue?

There are many definitions of fatigue. One definition of fatigue is “An overwhelming sense of tiredness, lack of energy and feeling of exhaustion” (Krupp et al 1996). This is a common symptom for many people affected by a neuromuscular disorder and is often caused by muscle fatigue.

What is muscle fatigue?

Muscle fatigue is different to general fatigue that most able-bodied people experience. Many people will say they are really tired after a hard day or stressful time. This type of fatigue gets better after a good night's sleep or in some cases, where exertion has been extreme, after a couple of days rest. This is not the case in neuromuscular conditions. Fatigue in some neuromuscular conditions can be:

- progressive – can get worse over time i.e., as the day goes on some people become more tired or as the week progresses some people feel exhausted by the time the weekend arrives
- variable – can change from one day to the next (or one hour to the next)
- persistent – on-going

What causes muscle fatigue?

When muscles are over-used, micro-damage is produced at cellular level. This tells the brain that the muscles need to be bigger and stronger to be able to go about day-to-day activities. In these cases, muscle is gradually built by stressing and damaging it with resistance such as weights or bands or undertaking the same activity over and over i.e. walking, running, cycling or specific exercise repetition using resistance.

After exerting this 'micro-damage', the muscles need time to recover in order to re-generate, repair and grow.

However, in neuromuscular disorders it takes less stress to damage muscle and the recovery period may take longer. As the muscle, or nerve supplying the muscle, is damaged (depending upon the condition), it can be more difficult to build the muscle or make it stronger.

In some cases, over-exertion can lead to persistent fatigue that can take longer to recover from. Some people report that after such exertion, they may be unable to get out of bed the following day and it can take a few days to recuperate and get back to where they were. The recovery stage in many ways is like a computer re-setting itself back to its default settings. Muscle recovery is a complicated process and there is no set time for this process. It will vary from person to person depending on the level of fatigue the individual experiences.

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Whilst activity is good for people with a muscle condition and activity keeps muscles working effectively and efficiently preventing de-conditioning, exercise is best undertaken within the individual's comfort and ability. Exercise that involves a progressive increase in the length of time it is being undertaken for (i.e. walking for 5 minutes instead of 3) or an increase in weight, resistance or number of repetitions within a short timeframe, is good for those who are in training but we do not generally recommend this for people with muscle conditions. Fatigue is different for everyone and for some people with a neuromuscular condition, undertaking day-to-day activities that are repetitive can be enough to cause muscle fatigue. Others may need to be more careful when exercising and be aware of when it is time to take a break.

Progressive fatigue symptoms

Fatigue can build up with continued muscle exertion throughout the day and some people find that they have energy in the morning but as the day goes on, their energy decreases. This is due to several factors:

- in neuromuscular conditions, muscles are weaker to start with and yet some people will expect their muscles to undertake the same daily tasks as other people
- because the muscles are weaker, they do not exert the same forces on joints and you can be pulled into awkward postures or move in less efficient ways. When moving less efficiently, you are using more energy and therefore will become tired more quickly
- joint and muscle pain can be a challenge and this reduces your energy stores. If you are in pain, it may not be possible to do the same amount of activity as others and you may become tired more easily
- as people age, they lose muscle strength. From around the age of 40 and onwards, you gradually lose muscle bulk. Loss of muscle due to the ageing process combined with muscle weakness from a neuromuscular condition can have a greater effect on your energy levels and it is important that those around you understand the reasons why you may feel tired

Variable fatigue symptoms?

Fatigue is also variable and that means you can be more tired one day than another for no apparent reason. On days when you are feeling tired, it is important that you do not overdo things. If you overuse tired muscles, you are more likely to trip or fall (see Supporting Information Leaflet (2): Falls Management).

Fatigue can also be variable within the day i.e. one minute you feel fine and the next you feel really tired. You may notice this in the amount of muscle work you do. For example, you may be able to lift an object a couple of times and then when you go back to do it again, you can hardly pick it up or your muscles start to shake or you feel very tired. This is cumulative fatigue and can be difficult for those around you to understand.

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Your family may feel that because you did it once, it should be easy to do again and in fact some people may feel that the more you do it the easier it should become. This is often not the case. One way to explain this is if you think of yourself starting with less power in your muscles than others, like a battery that is only partially charged. Because you didn't start with a full charge, your battery will run out quicker and the more often you use your muscles without re-charging, the quicker the battery will run out. This is also the case when your muscles are trying to re-set after they have become fatigued. The recovery phase also requires energy and if you have completely exhausted your energy levels, then recharging may take longer.

For most people with a neuromuscular disorder, muscles are not so good when working on a repetitive activity and particularly activities that require a lot of effort in short bursts. It can be frustrating if you feel that others may be thinking you are not trying hard enough when this is clearly not the case.

Joint damage

When muscles are tired, it can sometimes be more difficult to do even small tasks. Joints may be put under more strain which can cause damage to ligaments. Ligaments are the fibrous bands that connect bones at the joint. A sprained ligament can feel painful and debilitating causing further alteration to movement patterns which in turn causes more stress to the joints, so it is important that you minimise joint damage as much as possible.

How to manage your fatigue

There are different ways to manage your fatigue and managing fatigue can sometimes feel challenging depending on your lifestyle. You may work in a challenging job and some people are working whilst supporting a family at home.

When managing fatigue we talk about planning, pacing, and prioritising.

1. Planning

If you know what you are doing over the period of a day, then you can plan the more energetic tasks for the time of day when you have more energy. For some people this could be first thing in the morning. For others it may be late morning because after a shower and personal care, they may need a rest. Some people have their shower or bath at night time as this can be exhausting and it means they can go straight to bed after they have bathed and attended to their personal care.

It is a good habit to pace yourself every day, but it is also important to pace yourself over the week. For example, if you work part time, try, and have a rest day in between rather than clustering your working days together. If you are going out on an evening, try and plan it so that the following morning will not be too energetic.

Start to be aware when doing everyday activities. Find out what makes you tired or causes you pain. Everyone is different and in fact, your energy levels will be different

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on a day-to-day basis. It is important that you 'tune' in to how your muscles are working so that you can change your activity if needed.

If there are specific activities within your working day that cause you fatigue, discomfort, or pain, speak to your teacher or manager to see if you can change these. This could be lifting objects, sitting, or standing in the same spot for long periods of time or undertaking a repetitive activity including walking.

If there are tasks that you are unable to change, try and undertake them for a shorter period and then switch to another task. Come back to the original task and then switch again. Breaking down tasks into smaller chunks is also a good plan for both work and at home. If you are on your feet sit down frequently and if you are sitting, stand up and move around as often as you are able.

Break your day into three segments, morning, afternoon, and evening. It is good practice to try and work your day so that you have no more than two busy segments in your day. Have at least sometimes where you can chill out. If you work a full day, you may want to take it easy in the evening and not do housework.

If you do housework in the morning, try and rest during the afternoon particularly if you have a family who will need their dinner when they come in from school. If there is more than one person in your household, ask them to help with daily tasks and spread the load...learn to delegate!

2. Pacing

Pacing means slowing down and taking your time i.e. spacing out the jobs you have to do. Most people with neuromuscular disorders find that after a certain amount of time of doing a single activity, their muscles will start to tire. This is very much an individual thing and can be different from day to day. Some people can sustain an activity for an hour or so whilst for others it may be a few minutes. Some people will feel a burning sensation in their muscle when they have overdone a particular activity and at this point it would be wise to stop and rest. Resting does not always mean doing nothing. It may be that switching to a different activity will be enough to give that muscle group a break.

It is important to recognise symptoms of fatigue which can be variable. Muscle fatigue can feel like burning in the muscle, cramp, shakiness, weakness or pain. If you feel these symptoms, then this will be a good time to change what you are doing or maybe take a break. In time you will be able to develop an understanding of when these symptoms will occur. Before you reach the stage of fatigue, your brain will send a warning. This tends to be an emotional response such as:

- **frustration** (I'm just going to keep going until I finish this task)
- **anger** (leave me alone...can't you see I'm busy)
- **tearful** (I'm really fed up feeling this way, no-one understands)

When you feel this way, this is a good time to change what you are doing and give your muscles a rest before the physical signs of muscle fatigue start.

At home it is good to get into the habit of breaking jobs down, i.e. dusting for a short period of time, then switching to vacuuming, then to a seated chore and back again. Initially, this may feel “bitty” but any new way of working can take a while to get used to and if you do this regularly, it will soon become the norm.

If you are undertaking an activity two or three times to complete it, such as hanging up a coat or getting up from a chair, then you may have to do this activity in a different way. An Occupational Therapist (OT) may be able to supply an aid or gadget to help make things a bit easier or perhaps may even suggest an adaptation to help you. Continuing to use the same muscle groups to complete the activity can cause further fatigue in an already tired muscle group which in turn can lead to a fall or an injury. Some people find it helpful to join an online support group where they can talk to people with the same condition who may have found better ways of doing things and sharing experiences can be really helpful.

Sometimes, people think that by looking for an easier method to do things, they may become weaker or appear lazy, but this is most definitely not the case. Making things a little easier will preserve your energy for the more important things in life whilst making sure you are keeping safe from the risk of joint and muscle damage and falls. We call this energy conservation, and it is a good habit to get into.

3. Prioritising

This is a way of making sure that your quality of life is good. When planning your day, think of all the things you must do and all the things you want to do and prioritise the things you want to do that give you pleasure. When we are happy, our energy levels improve. If we are doing things we don't like because we “have to” day in and day out, we feel stressed, anxious and our mood can drop. If we build something we enjoy into our day, e.g., looking forward to a nice meal, a television programme, a shopping trip, a day out, hobby time etc, these are all good ways to lift our mood and spacing the “must do” tasks between these more enjoyable pastimes can improve energy levels.

Temperature

It is also important to remember that you can tire more easily when cold. When your muscles are cold, the supply of nutrients and oxygen are not as efficient as when they are warm. Therefore, many people with a muscle condition find they fatigue more quickly in colder conditions than when the weather is warm.

When cold, you tend to tense up your muscles and this causes you to move in poor postures which in turn increases the risk of muscle fatigue. Keep this in mind if you are going out and you may want to shorten your journey or plan more breaks where possible. It may also be worthwhile investing in thermal clothing that isn't bulky or heavy. The other extreme, of high temperatures, can also be debilitating as your body works hard to cool you down, leaving you feeling as though you have done a lot of work, so it is important to be prepared! This is an important consideration when going on holiday.

Understanding primary and secondary muscle fatigue

Primary fatigue is caused by the neuromuscular condition and the muscle weakness itself which we can do little about. Secondary muscle fatigue can be caused by additional external factors which we can have some influence over. Let's look at this in more detail:

- **medication:** Certain medication can cause fatigue. If you are feeling more tired than usual and have had a recent change in your prescription, then it is worthwhile discussing this with your GP
- **intercurrent illness:** If you have a cold, viral infection, temperature etc, this can also increase your fatigue symptoms. You will use your energy trying to fight off the infection or virus and lower your temperature so it may be that you will need more rest during these times. This is also true if your body is dealing with other conditions such as diabetes, thyroid problems etc as this means your body now has more than one condition to deal with and energy can be split to work on other areas that your body may need to address
- **pain:** Coping with chronic pain can also affect your energy levels so if you have ongoing pain, you should get advice from your GP, Consultant or Physiotherapist.
- **low mood:** Anxiety, stress, low mood and depression can affect your energy levels. If you have ongoing symptoms then you should discuss this with your GP or Consultant
- **nutrition:** It is important to have a varied and balanced diet. Poor nutrition, vitamin deficiencies and too much or too little calorie intake can affect your energy levels. If you feel you require further advice with regard to nutrition, you can get advice from your GP or Dietitian
- **sleep:** If you have a poor sleep pattern or wake frequently throughout the night, this can affect your energy levels (See supporting information leaflet 7: The importance of sleep). If you feel you have disturbed sleep then it may be useful to further discuss this with your GP, Consultant or physiotherapist
- **exercise:** Just as overactivity can cause muscle fatigue, so can underactivity. If muscles become deconditioned, they don't work effectively or efficiently. Your physiotherapist can advise (see supporting information leaflet 5; Stretches and Exercise for people with a neuromuscular disorder)

These are just some of the additional factors that can make you feel more tired, but this list is not exhaustive. There may be other reasons why you are more tired at certain times than others. Tuning into your body can help you manage your fatigue levels and being aware of things that make you feel better or worse is an important step in your overall fatigue management.

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Further information

If you would like more information on fatigue management, please contact:

Marina Di Marco
Consultant Neuromuscular Physiotherapist
marina.dimarco@ggc.scot.nhs.uk