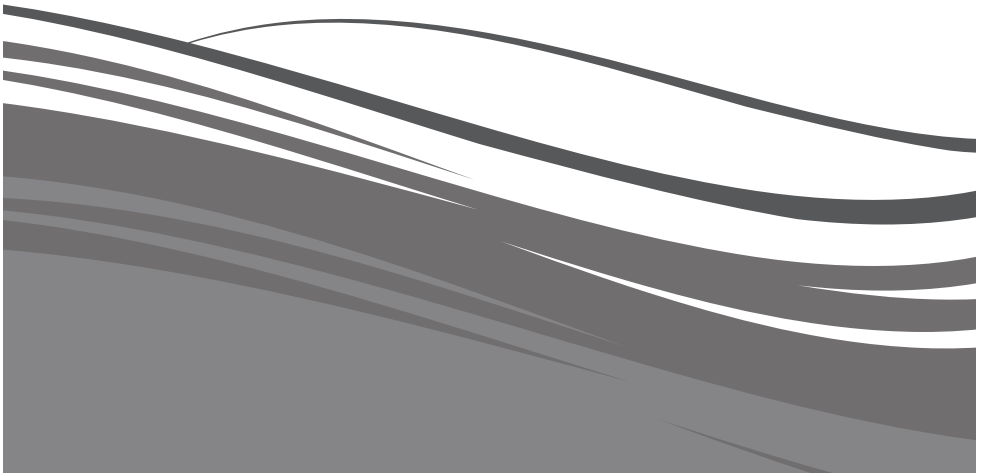


Fatigue in Myasthenia Gravis

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Fatigue is very common in myasthenia gravis (MG). Probably 80% of patients or 4 out of 5 MG patients have fatigue that affects them in their every day lives.

Fatigue is different from weakness due to myasthenia. One definition of fatigue is:

“An overwhelming sense of tiredness, lack of energy and feeling of exhaustion”. (Krupp et al 1996).

Fatigue is also common in patients with other neuromuscular and neurological disorders, and many will describe it as a lack of energy, feeling exhausted and unmotivated. It is therefore some thing that not only affects our body, but our mood, our thinking ability and our emotions. It can sometimes feel as though your brain is too tired and cannot think straight or make decisions. Some people refer to the latter as “brain fog”.

Increasing the medication for the MG does not improve the symptoms of fatigue. Also, pure rest and inactivity do not help to improve fatigue or energy levels, however, rest is relevant when your myasthenia symptoms are active.

What factors cause Fatigue?

Many factors often result in fatigue and usually there isn't just one problem that is causing fatigue.

- 1. Muscle weakness**, due to MG, results in physical activities becoming harder to do. You have to work harder to achieve what you previously considered as a simple task.
- 2.** If the muscles are weak, the brain will send signals back to the muscles instructing the body to do less. Our body does less, and this in turn feeds back to the brain that it is tired after doing less than before. This results in an endless cycle of mis-signalling which will result in you feeling sluggish and fatigued. However, if we do less our muscles decondition quickly and we breathe faster even if the exercise is minimal (low-load).

- 3. Poor sleep pattern.** Sometimes the medications that you take for your MG interfere with your sleep (for instance steroids). Once established, it may be difficult breaking that cycle of poor sleep and insomnia (difficulty falling asleep) may become a pattern. This accumulates and results in further feelings of fatigue.
- 4. Pain.** Although pain is not common in MG, some patients suffer from pain for other reasons for example arthritis. Having to deal with chronic pain makes us tired. The medications that relieve pain can often make us tired too.
- 5. Low mood, anxiety, chronic feelings of frustration and anger, and depression.** All of these emotions make us feel chronically tired and interfere with our “get up and go”. These feelings may also interfere with our sleep, our relationships and our eating habits.
- 6. Poor nutrition and hydration.**
- Many MG patients gain weight due to their steroid treatment and because they are physically less active. They may then avoid eating regular meals or eat the wrong foods to try to lose weight. It may sound obvious, but our bodies only function well when we feed it the right kind of fuel. And where does this fuelling come from, if not from the food we eat on a daily basis?
 - Likewise, our body is mainly made out of water. If we don't drink the right amount of water throughout the day, we will become dehydrated and feel very tired. Some people fall into the trap of drinking caffeine to perk them up. Too much caffeine can in fact dehydrate you and in time make you tired and also may interfere with your sleep pattern if you drink caffeine too late at night.
 - Some people find that the “carbohydrate fix” becomes a regular habit. Carbohydrates are food that burn down into energy quickly and are more associated with bread, grains, cakes, crackers, cereals and sweet foods. However, too many

carbohydrates result in weight gain. Carrying more weight, means we need to work harder to get from “A” to “B” and this makes us more tired. The effect of the carbohydrate “fix” only lasts for an hour or two, and too many carbs can interfere with and lower our mood after the initial “high”. So, don’t fall into this trap! It may be worth looking closely into your diet to see what you can change to improve your symptoms.

Managing your Fatigue

We know that managing your fatigue can be challenging and requires a holistic approach, meaning that we need to look at all possible factors that are resulting in your fatigue. You will need to change your lifestyle.

When managing fatigue, we talk about **Planning, Pacing and Prioritising**.

Planning: For instance, if you feel more energetic in the mornings then do the tasks that need more energy in the mornings, and do your other tasks later in the day. Try to identify the activities that make you feel tired for instance showering. You then plan to rest after your shower or you shower before going to bed at night. Try to plan your day and week accordingly.

Pacing: This means that you space out the jobs that you need to do. Break down the chores in the house that make you feel tired. Aim to do one chore a day if more results in pain or weakness or fatigue. Only climb upstairs once if this makes you exhausted. Learn to delegate to family and friends if you cannot do it all.

Prioritising:

If you cannot do it all in one day, only deal with the tasks that need dealing with first. Make a list and decide for yourself which task is really important and needs dealing with first.

Other aspects of fatigue management:

Rest versus physical activity and exercise

Rest periods are important especially when the MG is active and you are still experiencing fluctuating and variable muscle weakness. Too much rest or sleep however can have a negative impact on our energy levels. If we nap too long in the afternoons, this can disrupt our normal sleep pattern at night and we are then unable to fall asleep at the usual time at night. Rest needs to be balanced against some physical activity and exercise.

It is a fact that walking, stretching, in fact any exercise releases chemicals in our body (endorphins) that improve our mood and make us feel better. The positive changes that take place in our muscles with exercise are amazing for everyone and are sustained if you continue to exercise. The exercise does not need to be intense. You don't need to go to the gym. Planning a gentle walk during your day, if you are able, can have many benefits and can improve your energy levels. Swimming is also another type of exercise that can be beneficial for you. Regular stretching is important for the muscles and joints. If we don't regularly stretch then our muscles and joints will become painful. Stretching exercises that some

people find easy include Tai-Chi. Pilates and yoga can be beneficial but are somewhat more difficult.

When you first start exercising, the body finds it hard work. As you start doing this regularly, the muscles "recondition" which means that the muscles are learning to stretch and be used again and you build stamina over time. As you continue to exercise, this becomes easier and in time you will find that you are able to do more and that your energy levels improve. As you increase your exercise levels, you will find that you will sleep better too.

Always check with your consultant or your specialist MG nurse that you can do certain types of exercise.

Healthy nutrition

Eat regularly, the right kinds of food and the right quantities. Try to lose weight if your BMI (Body Mass Index) is high (if we carry too much weight then we will feel chronically tired). People who are overweight tend to snore when they are asleep and may be at risk of developing obstructive sleep apnoea. Reducing weight reduces this risk and sleep improves.

Drinking plenty of fluids is important, preferably water. Caffeine tends to make us feel better/gives us a boost for a short time but will dehydrate us. If we are dehydrated then we feel tired. Too much alcohol can relax your muscles, which may have a negative effect on your MG. It can also make you more tired and if you take regularly may end up interfering with your sleep pattern.

Sleep

Regular sleep helps our energy levels. Avoid using your phone, I-pad or other electronics (including TV) at night as they transmit “blue light”. The blue light can interfere with your sleep pattern and prevent you from going to sleep because it makes your brain active. Before going to sleep, dim the lights and prepare your body to wind down and calm down. Do things that calm you down before going to your bed at night, for instance read. Don't eat or drink foods that are likely to perk you up before going to bed for instance caffeine, sugary drinks or foods.

Reducing stress and improving your mood

This can be difficult and sometimes we cannot change our lives or circumstances. Being philosophical and accepting reality is an important step. Over-thinking and worrying does not achieve anything. Outbursts of anger waste energy and don't solve your problems.

Distraction techniques can be helpful: something makes you angry – don't reach out for the biscuits or go in a rage, but go for a short walk or out in the garden or grab the newspaper or book instead.

Relaxation techniques

Individuals use different techniques to relax. Some people find meditation and mindfulness helpful to relax. Meditation has been shown to bring our heart rates down and make us feel calmer, but more importantly it helps people feel they have more energy to deal with the day ahead of them.

Hobbies

Indulge in activities that you enjoy and that will allow you to focus, concentrate, and enjoy yourself. Taking your “mind off things”, forgetting all your worries, distracting yourself and doing something that you enjoy can relax you and make you feel better. This may include: gardening, painting, knitting etc.

Apps

There are many apps that you can download onto your phone and that you can use at any point in the day or before going to bed. These apps help deal with relaxation, stress management, helping you to sleep, learning to breathe efficiently etc. One such helpful app is “Headspace”.

Conclusion

All this seems “common sense”. But sometimes we end up forgetting to deal with the simple things in life. MG is a chronic condition. The medicines (for example steroids, pyridostigmine) and thymectomy (surgery to remove the thymus) help to stabilise the condition. After the “acute” phase – after the initial presentation of MG or a MG relapse (blip) comes the recovery phase. To repair the muscles we need to deal with the other factors, which we discussed above. Remember, the immune system (which helps us also to fight off infections) works better when we are relaxed, and not stressed. Also, exercise, positive attitudes, healthy diets and regular sleep improve our immune system and of course our overall wellbeing.

For more information on Fatigue, visit www.smn.scot.nhs.uk (under Patients and Families; other useful information).

