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Fatigue in MSA

We know that fatigue is a symptom that affects a lot of people living with MSA (in fact the last MSA Trust survey 96% of people living with MSA indicated it was a symptom for them.) It is therefore important to look at ways of managing fatigue. This short factsheet has been put together to help people with MSA identify and manage difficulties with fatigue. Occupational Therapists are good at assessing fatigue and working with all the multi-disciplinary team (MDT) to help manage the problems.

What is fatigue?

Fatigue can present itself as an overwhelming sense of tiredness, lack of energy and feeling of exhaustion and is different from the sense of tiredness people without MSA experience. Fatigue can have a significant effect on a person's ability to deal with day-to-day activities. Fatigue can also affect the person's cognitive ability, speech, wellbeing, relationships and mood.

Recognising fatigue

If you feel you may be affected by fatigue, a useful way to check is to see if you have six or more of these symptoms:

- Diminished energy, or increased need to rest, disproportionate to any recent change in activity level
- Feelings of general weakness or limb heaviness
- Diminished concentration or attention
- Decreased motivation or interest to engage in usual activity
- Insomnia (little sleep) or hypersomnia (excessive sleep)
- Experience of sleep as un-refreshing or un-restorative
- It takes a real effort to get going or get on with a task
- Overwhelming emotions around feeling fatigued
- Feelings of problems with short term memory

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- Post-exertion malaise (feeling out-of-sorts) lasting several hours.

What causes fatigue?

There are numerous causes of fatigue in MSA and it is often listed as a symptom for most diseases and conditions. We don't yet know what causes it in MSA but it is likely to be a number of factors related to your other symptoms. These fall into four general areas: physical, emotional, environmental and biological.

Physical aspects

Deconditioning – having MSA means a greater effort is needed to be mobile. This can lead to using muscles less, which in turn can lead to changes brought on by lack of use, which can then cause fatigue. It is important you talk to your Physiotherapist about this.

Lower blood pressure – this may well cause fatigue and should be checked and treated where possible. We have a factsheet about blood pressure and dealing with postural hypotension which you can request using the contact information at the end of this factsheet.

Sleep disturbance – sleep problems are common in MSA and addressing these can help improve your sleep which can in turn help reduce fatigue.

Extra effort – this is the increased energy expenditure due to the extra effort needed to do everyday tasks e.g. washing, dressing and getting out of a chair.

Emotional aspects

Low Mood /Depression – this should be assessed for and treated. Low mood can lead to less motivation to be active, which can in turn lead to fatigue.

Environmental aspects

Lighting – poor lighting causes increased visual effort which can cause fatigue.

Temperature – extreme temperatures, for example a heatwave in the UK or getting too cold in winter, can cause fatigue

Noise – too much auditory stimulation can cause fatigue

Biological aspects

Medications – it is important to monitor if any changes in medication make fatigue worse. Make a note of any medication changes and any changes in fatigue and discuss with your GP or specialist.

Infection – any infection can make MSA symptoms worse and so it is important to be aware of the risk of infection and treat infections promptly. It is very important to be aware that the lack of a high temperature does not rule out the possibility of infection.

Low blood levels - it may be helpful to have some routine blood test checks for anaemia, Vit B12, Folic Acid, Vit D and thyroid test as well as checking some of the blood chemicals eg potassium, magnesium and calcium. Any deficit in any of these can contribute to excess fatigue and are treatable, so may help improve how you feel and cope with fatigue.

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Managing fatigue

If you are suffering from loss of energy, exhaustion or overwhelming tiredness then ask your Occupational Therapist to assess your fatigue and help you develop a management plan. They will also need to liaise with other members of the care team. You might want to consider the following areas:

Exercise and nutrition

A good balanced diet and as much exercise as you are able, may help combat fatigue. You should speak to a Dietician about your diet and a Physiotherapist about safe, beneficial exercises. Remember to drink plenty of water, this is so important for many aspects of MSA and is known to help fight fatigue.

Rest and relaxation

Getting a good night's sleep is so important but can be difficult. You can increase your chances of a good night's sleep by adopting good sleep habits and addressing issues of anxiety, pain and night frequency of urination. It could also help to learn some effective relaxation techniques. For more information about getting a good night's sleep please see our MSA News article in issue 43: <https://www.msatrust.org.uk/support-for-you/magazine/msa-news-issue-43/>.

The 3 Ps principle (Pace, Plan and Prioritise)

Learning to pace, plan and prioritise your daily activities will help you to save energy. It is important that you pace activities and allow plenty of time for rest and recovery. Break activities into smaller tasks and spread them throughout the day where possible.

Planning a weekly diary, balancing activities, and allowing quiet days will help manage your fatigue. Once you know your own pattern and levels of activity you can develop a realistic weekly plan and it will help you prioritise important events and activities, so you are still able to do the things that matter most.

Prioritise activities that you want to do. Don't be afraid to accept help or delegate things to others, either family, friends, or outside agencies. It is difficult to ask for support but the people around you will be happy to help.

Mood and anxiety

It is easier said than done but try avoiding stress, identify the things that cause stress and work out ways to reduce the problem; an Occupational Therapist will help you here. If the fatigue is caused by low mood then it might be worth considering therapy or medication, you should talk to your GP about this.

Medication

If you have found that medication could be a cause of your fatigue then discuss this with your GP or specialist.

Environmental changes

If you have sensitivity to heat and you feel it is affecting your fatigue levels then avoiding extreme temperature will help. Getting conditions right will give you the best chance to combat fatigue. Adaptations or alterations to your home environment may also help reduce the impact of fatigue. Some aids may be available free of charge so talk to your Occupational Therapist.

Using a wheelchair some or more of the time may help you to reserve energy for activities that are important to you. You may be able to get help with a short-term wheelchair loan or apply for the Blue Badge scheme, especially if you are unable to stand for too long or get tired walking long

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distances. These facilities may also be available to you if you are planning a short holiday or day trip, speak with your Occupational Therapist about wheelchairs.

Further support

If you develop or suffer with acute fatigue, you must discuss this with your GP or MSA Health Care Specialist as your symptom of fatigue may be unrelated to MSA. For example, you may suffer with 'anaemia' (low level of iron in your blood) or have an infection, which are all treatable.

Key points to remember

- If you are feeling overwhelmingly tired, have a loss of energy or feel exhausted you may be suffering from fatigue
- If you feel you are suffering from fatigue, then consult your Occupational Therapist
- Working with your care team you can develop a plan that will help you manage the issue more effectively.

The Trust's contact details:

We have MSA Health Care Specialists that support people affected by MSA in the UK and Ireland. If you would like to find the MSA Health Care Specialist for your area, contact us on the details below or use the interactive map here – <https://www.msatrust.org.uk/support-for-you/hcps/>.

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References for this information sheet are available by contacting support@msatrust.org.uk.

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