

Effects and self-management tips

Fact sheet for Myelodysplastic Syndrome (MDS) Patients

What is fatigue?

- Fatigue is a term used to describe a feeling of exceptional tiredness, lethargy or exhaustion, all (or most) of the time. Often this tiredness is not improved by sleep or rest.
- Fatigue is one of the most common symptoms experienced by MDS patients. Studies have found high levels of fatigue significantly impair quality of life in MDS patients.

What causes fatigue?

Levels of fatigue in MDS patients are influenced by a number of factors including:

- **Effects of MDS**
 - **Anaemia** Persistently low levels of haemoglobin (the blood protein that carries oxygen to the body's tissues), known as anaemia, can contribute to feelings of fatigue. It is important to note levels of fatigue and levels of haemoglobin are not comparable between patients; two patients with the same level of haemoglobin may not experience the same level of fatigue. Fatigue from anaemia is variable and can vary within patients themselves.
 - **Cytokines** In patients with MDS, blood levels of cytokines (molecules that cells use to signal to one another) are often abnormally high and these cytokines are well-known contributors to fatigue.
- **Other existing medical conditions/ exacerbation of symptoms of other medical conditions** Patients may have other conditions, alongside MDS, which contribute to feelings of fatigue. Symptoms or effects of these conditions may feel more prominent when coping with MDS as well and also contribute to fatigue.
- **Hospital visits for treatment** Traveling to hospital or to the doctor for appointments or to receive treatments is an additional physical and emotional exertion which may contribute to feelings of fatigue.
- **Stress and anxiety** Stress and worry about MDS, family, work, finances or any other concerns can be physically and emotionally draining, can prevent sleep and contribute to fatigue.

What are the effects of fatigue?

The effects of fatigue may not be independent from one another. Physical effects can lead to other sensory, behavioural, or emotional effects, while cognitive effects may lead to further emotional effects. It is important to remember that fatigue may affect you in ways beyond the initial feelings of tiredness.

Physical Overwhelming feeling of tiredness, lower energy levels, general sense of sluggishness, more need for sleep or rest, difficulty sleeping, dizziness, loss of sex drive, reduced appetite.

Sensory May feel pain due to muscle stiffness or weakness your activity levels are lower and you are moving around less.

Cognition May be difficult to concentrate, hard to focus attention, be difficult to remember things, have decreased interest in things, can feel overloaded.

Behaviour May avoid going out or engaging in usual activities due to anticipation of fatigue, may see family/friends less, accept fewer responsibilities, reduce work hours, take extra days off.

Emotions May cause feelings of frustration/ irritability. Some people express concern over never feeling 'normal' again or feeling like no-one really understands. Severity may change on a day-to-day basis. Usually people experience ups and downs or mood swings due to stress and anxiety.

Fatigue self-management tips

The treatments you receive for MDS (such as blood transfusions or drug therapies) may help ease the symptoms of fatigue. However MDS treatments are unlikely to take away the feeling of fatigue entirely.

The following self-management techniques can help reduce the effects of fatigue. Whilst they may not cure fatigue, these non-pharmacological interventions have been known to ease the effects, help people feel more in control and more able to manage with a reduced energy level.

Physical

- **Exercise** Even if exercise is the last thing you feel like doing when experiencing fatigue, staying physically active has shown to be one of the most effective ways of improving the effects of fatigue. By exercising as much as you feel comfortable (even if it seems minimal) you can improve the way you feel and your sense of wellbeing. Exercise can also stimulate a reduced appetite.
- **Nutritional interventions** Worries about nutritional intake should be discussed with your doctor. If your appetite is poor, try: drinking plenty of fluids; having smaller portions; eating whenever your appetite is best. You may also want to check our fact sheet [Nutrition: Information and advice & neutropenic diets for MDS patients](#), available on our website and from our office by request.
- **Sleep patterns** In order to maximise good quality sleep at night which will restore energy levels, try the following: have a regular sleep / wake pattern; keep as active as possible and avoid sleeping during the day; identify and/or write down your problems and worries well before going to bed; avoid caffeine and alcohol before going to bed; have your room at a comfortable temperature.

Emotional and lifestyle

- **Restorative experiences** Engaging in activities and experiences that are enjoyable and relaxing can help break the cycle of lethargy and help return to what feels a more normal way of living. Walking in the garden or participating in art/crafts can help combat cognitive and emotional elements of fatigue.
- **Managing stress and anxiety** Stress and anxiety may be related to your feelings about your MDS or your fatigue. Feeling stressed or anxious consumes a lot of energy and prevents sleep. Talking to your friends/family/doctor, contacting support groups or attending support group meetings can provide an outlet and can be a very effective way of reducing stress and anxiety. Finding ways to help you relax or pass times which distract you from feeling stressed or anxious (such as listening to relaxing music) can help you to sleep at night and therefore help reduce fatigue during the day.
- **Changing ways of doing things to conserve energy** It is often difficult for people experiencing fatigue to get used to a reduced energy level. Planning and deciding on priorities is a good way of being in control of an energy level that is less than it used to be. Try to use energy on the things you really need or want to do. Avoid an all or nothing approach, going all out on a good day (when feelings of fatigue are not as strong), which leaves nothing in reserve, often resulting in days of exhaustion. Try to avoid this pattern of extremes by doing a little less on your good days to enable you to achieve more on your not so good days. You will be able to do more over time with a more balanced rate of activity. Remember to take regular breaks during strenuous or activities which may take a long time, such as gardening. Even if you don't feel like you need a break at the time, breaking up an activity with rest periods will help you to pace yourself.
- **Sharing your work load** The effects of fatigue may mean you are unable to do all the things that you used to. Delegating or asking others to share tasks (such as laundry, cooking, cleaning, shopping) can help reduce the number of things that take your limited energy and may help you to manage.

References and further reading Full articles available on MDS UK website or contact our office for paper copies

Julie Burkin, Occupational Therapist, Fatigue and Fatigue Management, *presentation prepared for MDS UK*

Dr David Steensma et al., (2008) Common troublesome symptoms and their impact on quality of life in patients with myelodysplastic syndromes (MDS): Results of a large internet-based survey, *Leukaemia Research*, 32 (5), pp. 691-698.

Tanya Navarro, Occupational Therapist, Fatigue, *presentation prepared for MDS UK*

Acknowledgements Thank you to Julie Burkin, Dr Steensma and Tanya Navarro.

Please note this fact sheet is a guide and should not replace the advice of your clinical team. Date Published August 2012