

# Fatigue

## Effects and self-management tips

### Fact sheet for Myelodysplastic Syndrome (MDS) Patients

#### What is fatigue?

- Fatigue is the term which describes a feeling of exceptional tiredness, lethargy or exhaustion, all (or most) of the time. Often this tiredness is not improved by sleep or rest.
- Persistent fatigue is one of the most common symptoms experienced by MDS patients. Studies have found high levels of fatigue significantly impact 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 can differ between patients; two patients with the same level of haemoglobin may not feel the same level of fatigue. Studies show anaemia-related fatigue can be more manageable in patients with a strong cardio-vascular system, and without other medical conditions.
  - **Cytokines** Blood levels of cytokines (molecules that cells use to signal to one another) are often abnormally high in patients with MDS, which can contribute to ongoing 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 of other conditions may feel intensified when a patient is also coping with the effects and treatments for MDS.
- **Hospital visits for treatment** Travelling to hospital or to the doctor for appointments or treatments is an additional physical and emotional load which can contribute to feelings of fatigue.
- **Stress and anxiety** Stress and worry about MDS, and its impact on family, work and finances can be physically and emotionally draining, can disrupt sleep and eating patterns; all contributing to fatigue.

#### What are the effects of fatigue?

The effects of fatigue may not be independent from one another. Being unable to physically do everything you have before can lead to other sensory, behavioural, or emotional effects, all of which can increase fatigue, so it can be a vicious circle. There is a strong link between fatigue and feeling depressed, and it is important to recognise that feeling physically drained 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, but difficulty actually sleeping. Dizziness, loss of sex drive, reduced appetite.

**Sensory** May feel pain due to muscle stiffness or weakness, due to lower mobility and generally doing less.

**Cognition** Difficulty in concentrating & focusing, and in remembering things; decreased interest in hobbies, external events; feelings of overwhelm. (More common during early, 'adjustment' period).

**Behaviour** Less inclination to go out or engage in social activities due to anticipation of fatigue; may see friends less; accept fewer responsibilities, reduce work hours, take extra days off.

**Emotions** Frustration/ irritability. Some people worry about never feeling 'normal' again. Feeling like no-one really understands. Severity may change on a day-to-day basis. It is normal to 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 physical symptoms of fatigue. However, treatments are unlikely to take away the feeling of fatigue entirely, and can take a few weeks or even months to make a noticeable difference.

The following self-management techniques can help reduce the effects of fatigue. Whilst they may not cure it, these non-pharmacological interventions have been known to ease the effects and help manage energy levels.

### Physical

- **Exercise** Even if exercise is the last thing you feel like doing when experiencing fatigue, staying physically active has proved 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, more good quality food = increased energy levels.
- **Nutritional interventions** Worries about nutritional intake should be discussed with your doctor. If your appetite is poor, try eating better quality, nutritionally rich foods in smaller portions, more often. Drinking more fluids and incorporating foods like nutritional shakes, bone broths and smoothies may help.
- **Sleep patterns** In order to maximise good quality sleep at night, which will help with energy levels, try the following: have a regular sleep / wake pattern; keep as active as possible and avoid sleeping for long periods during the day; identify and/or write down your problems and worries well before going to bed; avoid caffeine and alcohol for four hours before going to bed; keep 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 you 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 having MDS or your fatigue. Feeling stressed or anxious consumes a lot of energy and disrupts 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 which distract you from feeling stressed or anxious (such as listening to relaxing music or audiobooks) can help you to sleep at night, and therefore help increase energy levels during the day.
- **Changing ways of doing things to conserve energy** It can be difficult for people experiencing fatigue to get used to a reduced energy level. Planning and prioritising is a good way of managing energy levels that are lower than they used to be. Try to prioritise 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, can result in exhaustion afterwards. Try to avoid this pattern of extremes by doing a little less on your good days, keeping a bit back to achieve more on your not-so-good days. You will find you are able to do more 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 are sure you can carry on 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 feel more in control.

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Please note these guidelines do not replace the advice of your clinical team. Date Published Aug 2012; revised Jan 2026