



# **Fatigue and Myeloma**

Cancer related fatigue (CRF) is defined as a "distressing, persistent and subjective" feeling of physical, mental or emotional tiredness related to cancer and/or cancer treatment interfering with usual functioning. This tiredness is not proportional to recent physical activity and is unrelieved by sleep and rest. Fatigue is recognised as one of the most common and debilitating symptoms of myeloma. Understanding the cause and adopting strategies to manage fatigue can help improve quality of life.

## **Symptoms of Fatigue**

**Physical** – Unrelenting tiredness, weakness, feeling sluggish or slow, heavy limbs, difficulties completing routine tasks or participating in recreational hobbies.

**Mental** - Impaired concentration and memory, absentmindedness, difficulty understanding simple instructions, difficulty processing information, irritability, forgetfulness, negative or unpleasant emotions, mental fog.

**Social** – limited ability to socialise, unable to fulfil usual role within the family or friendship group, impaired relationships, feelings of isolation.

### What causes fatigue?

CRF in myeloma is multidimensional and remains poorly understood. It is thought to be caused by changes in cellular physiology and heightened by symptoms such as pain, infection, anaemia and renal impairment, all of which can become more severe during myeloma treatment.

Other contributors include reduced activity, inadequate diet and fluid intake, psychological stress such as depression or anxiety, insomnia, nausea and treatment toxicity.

# How do treatments for myeloma cause fatigue?

As myeloma cells die, they release cytokines, which are substances that upset the normal chemical balance in the body. This effect can be amplified when treatments accelerate the rate of myeloma cell death.

**Chemotherapy** requires a significant amount of energy to eliminate rapidly dividing cells, both cancerous and healthy. It can also cause nausea and in some cases mouth ulcers, making it difficult to maintain adequate nutrition. Chemotherapy can also cause anaemia related fatigue and a profound decrease in muscle strength.

**Targeted Agents** such as immunomodulators, thalidomide (Thalomid®), lenalidomide (Revlimid®) and pomalidomide are associated with notable fatigue, as are protease inhibitors, such as bortezomib (VELCADE®) and carfilzomib (Kyprolis®). These treatments may also help relieve fatigue as the myeloma activity reduces.

**Steroids** may cause insomnia and muscle weakness that can lead to fatigue. They are also known to cause changes in mood and energy levels. It is recommended steroids be taken early in the morning to avoid insomnia.

**Stem Cell Transplants** are associated with fatigue due to the intensity and duration of the treatment. The fatigue usually improves with time as general wellbeing and fitness return. However, some people report experiencing residual fatigue up to one year after their transplant.

**Radiotherapy** related fatigue can develop over time and is the effect of the body repairing damaged cells. It usually lasts 3 to 4 weeks after the completion of radiotherapy but may last up to 3 months.

**Other medications** given for pain management (opioids), anxiety (anxiolytics), depression (antidepressants), nausea (antiemetics), insomnia (benzodiazepine, hypnotics) can cause medication related fatigue and enhance the effects of fatigue from other causes.

For more information about steroids please see Myeloma Australia's Steroid Therapy fact sheet on their website www.myeloma.org.au or by phoning head office for a copy 1800 693 566

### What can be done to lessen fatigue?

It is known that people who exercise and participate in psychological intervention during and after treatment experience improved CRF. These interventions are most effective when delivered using group-based and in person formats.

Other helpful interventions can include enlisting nutritional support via a dietitian, sleep therapy and being mindful of daily activities to conserve energy.

Treatable causes of fatigue such as anemia, infection, pain and dehydration should be managed by the treating team.

#### **Exercise**

Research continues to show that a regular exercise program to improve muscle strength is a very effective way to reduce fatigue. Participants in a UK study found that adhering to a program that included stretching, aerobic and resistance exercises reported having a better quality of life. However, both aerobic and anaerobic exercises are effective in reducing CRF. Without specific exercise recommendations for CRF please note the Australian physical activity guidelines for people aged 18-65 is moderate physical activity on most days of the week, with muscle strengthening activities on 2 of those days.

A daily walk around the block or even to the letterbox and back is a good place to start as well as breaking up long periods of sitting as often as possible. Supervised training and group based exercise regimes are known to increase motivation and adherence. There is also evidence that motivational interviewing and behavioural counselling lead to increased physical activity.

Activities such as Yoga and Tai-Chi combine gentle exercise and deep breathing which can also help to boost energy levels. Other benefits of exercise include: increased self-esteem, improved mood, regained independence, increased stamina for walking, standing and general daily household tasks, a possible shorter hospital stay and an improvement in quality of life.

A physiotherapist or an exercise physiologist can design a tailored exercise plan that considers limitations such as fitness levels and pain. The doctor should be consulted before lifting any weights to ensure bone damage does not occur.

Up to 5 visits to a physiotherapist, exercise physiologist or other allied health professional are covered by the Medicare Chronic Disease Management Program. For more information on this program please call Medicare on 132 011 or speak to a specialist myeloma nurse on our support line 1800 MYELOMA

# Psychological interventions

The most effective mode of psychological intervention to improve the effects of CRF according to recent research is cognitive behavioural therapy (CBT).

CBT uses strategies to positively manage thoughts, behaviour and emotions around a certain goal. This assists in the development of personal coping strategies. Other interventions include psychoeducation, cognitive or behavioural therapy alone, relaxation techniques, meditation, spiritual practices, talking with others, and counselling can all be beneficial. These self help techniques can provide a sense of control of the situation.

Social support including support groups is also an effective intervention, as well as a useful place to learn from the experiences of others and to share management strategies.

#### **Nutrition**

If nausea or loss of appetite are preventing adequate food intake, the body will not have enough energy to perform activities of daily living. A balanced diet that includes foods that supply iron and energy, such as green leafy vegetables and red meat, is recommended. Eating more frequent, smaller meals or snacks throughout the day should help to maintain enough nutrition when appetite is affected. Fruits, nuts, cheese and crackers are all great nutritious snacks to keep handy or high protein supplements to ensure maximum calories with minimum effort.

It is a good idea to cook when energy levels are highest, freeze extra food and accept help from family and friends to maintain nutrition. You can also consider home meal providers such as Meals on Wheels.

Maintaining adequate fluid intake is also important to flush through the toxins and waste products that can also cause fatigue. Keeping a water bottle close by will help maintain hydration throughout the day. Aim for 2-3 litres/day unless the kidneys are impaired and the doctor has enforced a fluid restriction.

For more information about nutrition please see Myeloma Australia's Nutrition and Myeloma fact sheet on their website www.myeloma.org.au or by phoning head office for a copy 1800 693 566

# Sleep therapy and energy conservation

Sleep therapy techniques such as stimulus control, sleep hygiene and sleep restrictions can help reduce CRF.

Stimulus control includes going to bed and waking up at the same time, and getting up if sleep doesn't come easily. Sleep hygiene is identifying and altering lifestyle habits. For example, limiting caffeine intake to combat insomnia. Sleep restriction includes maintaining a regular sleep pattern where possible, limiting naps and not over sleeping.

Energy conservation is the deliberate management of personal energy to prevent depletion. It can be useful to keep a diary to record fluctuating energy levels. This will help in planning activities for the time of day when energy levels are typically higher. Acknowledging signs of fatigue and accepting lifestyle changes can also help to manage the effects.

### **Mornings**

Rise at the same time each day, perhaps 7am to 7.30 am. Go outside, maybe for a walk and/or have breakfast outdoors. Take steroids (Dexamethasone, Prednisolone) early in the day to reduce sleeplessness.

### **During the day**

When tired, the body is most likely requesting a rest. If thoughts are worrying, set aside time during the day to deal with them if they are preventing sleep at night Avoid caffeinated products like tea, coffee, chocolate or cola drinks in the afternoon or evening. Napping can be beneficial for some people. It is important to limit naps to around 30-60 minutes to avoid interfering with night sleep patterns.

### Night time

Avoid going to bed too early, as this does not encourage deep sleep. Try going to bed around 10pm to 10.30pm. Getting up and going to bed at the same time each day helps the body maintain a regular sleep pattern. Eating rich food or exercising too close to bedtime can make sleeping difficult. Make sure the sleeping environment is not too hot or cold and avoid watching television, using electronic devices, e.g. iPad or iPhone or reading in bed. This helps the body to associate the bedroom with sleep.

If sleep does not come easily, get up and do something quietly distracting until tiredness is experienced again. Most importantly, do not get concerned if sleep is being evasive. Just lying quietly in bed can be as beneficial as sleep.

If considering taking a natural supplement to aid sleep, speak with the treating team. Some of these medications interrupt the effect of myeloma treatments.

#### **Activities**

Taking time to partake in special interests is important. Hobbies such as listening to music, reading a book or social outings can help distract from the fatigue or illness. Relaxation, meditation, aromatherapy gentle massage and for some people, reflexology, can also help reduce the effects of fatigue.

For further information on support groups visit our website at www.myeloma.org.au or speak to a specialist myeloma nurse on our support line 1800 MYELOMA

# What medical treatments might be needed for fatigue?

#### **Blood transfusions**

Anaemia is the term used to describe a low haemoglobin level. Haemoglobin in red blood cells is responsible for carrying oxygen around the body. Low levels can cause symptoms of dizziness, shortness of breath or tightness in the chest.

Anaemia can be treated with a blood transfusion or drugs to increase the production of haemoglobin. If there are no symptoms, treatment may not be necessary. The body can adjust to a lower than normal haemoglobin level if the decline is gradual and within an appropriate limit.

#### Infection treatment

Myeloma and/or the treatments increase the likelihood of an infection. A fever, which is a temperature of 38°C or above, is a sign of infection. It is recommended that patients have a thermometer at home and check their temperature if they feel excessively warm or hot, or develop the shakes (rigors).

If a patient's temperature is 38°C or above medical attention must be sought immediately

In some cases prophylactic antibacterial and antiviral medication may be prescribed to prevent infections. It may also be appropriate to have the flu vaccination. The doctor will advise if any of these measures are necessary.

The information in this fact sheet is not intended to replace medical care or the advice of a physician.

A doctor should always be consulted regarding diagnosis and treatment.

For further information please contact one of our Myeloma Support Nurses on our Support Line: 1800 MYELOMA (1800 693 566)

or visit our website: www.myeloma.org.au

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