

MANAGING CANCER-RELATED FATIGUE

An information sheet for patients, families and whānau



Cancer-related fatigue is the term used to describe extreme tiredness and is one of the most common, distressing and under-addressed symptoms in people living with or beyond a blood cancer.

As many as 9 out of 10 people with cancer (90%) get cancer-related fatigue. It is not improved by rest and affects people physically, psychologically and socially; making it hard to complete normal everyday activities. It sometimes improves when treatment has finished but for some people it may last for months or years.

Cancer-related fatigue can have many different causes including symptoms of the disease or side-effects of treatment. Some of these symptoms or side-effects may be linked together which can cause a cycle of fatigue.

People with fatigue are often incorrectly advised to rest and limit activity. However, physical inactivity causes muscle weakness, increased stiffness and pain, and this may make fatigue worse.

Fatigue is often linked to several physiological and psychological symptoms such as depression, anxiety, anaemia, weight loss and pain. These symptoms are linked to one another and can make each other worse which makes fatigue difficult to manage.

It is important to speak with your doctor to find out which symptoms might be making your fatigue worse. In this factsheet you will find some practical tips for managing your fatigue.

10 TIPS FOR MANAGING FATIGUE

1. Keep a fatigue diary

- a. Write down the times of day when you feel your best and when you feel most tired. This will help you figure out when you generally have the most energy and can help with planning and prioritising. A diary can also help you become aware of your signs of fatigue for example, short temper, low mood, increased pain.
- b. Ask your LBC Support Services Coordinator for an LBC journal to use as your fatigue diary.

2. Talk to your doctor or nurse if you experience fatigue

- a. It is very important to let them know how fatigue affects your life.
- b. Write down any questions that you want to ask at your next appointment.
- c. Take your fatigue diary with you (tip 1).

3. Address and manage any psychological effects of diagnosis/treatment

- a. Let your doctor/nurse know if you have any symptoms of anxiety, stress or depression.
- b. Make time for activities that help you relax such as seeing friends, reading or listening to music. Activities in nature such as sitting in a park or watching nature may also help improve concentration and problem solving.
- c. Use relaxation techniques and exercises such as mindfulness through a mindfulness based stress reduction course or a relaxation app.

4. Know your numbers

- a. Anaemia is a common cause of fatigue so it is important to keep an eye on your red blood cell count or haemoglobin (Hb) level.
- b. Monitoring your Hb level in a fatigue diary (tip 1) can help you see how your level affects your everyday life and level of fatigue.
- c. A blood transfusion can improve feelings of well-being and can quickly improve feelings of shortness of breath and fatigue.

5. Make sure you eat well and drink plenty of water. Poor nutrition and dehydration can cause a lack of energy, which can result in fatigue (please refer to LBC Eating Well Factsheet or Eating Well Webinar for more information)

- a. Let your doctor/nurse know if you have any nausea or vomiting.
- b. Eat a balanced diet which is important for energy.
- c. Have someone prepare meals for you so you're not too tired to eat, or choose ready-made meals.
- d. Have plenty of nutritious snacks and drinks in the house so you can have something when you feel like it.
- e. Make a note of what and when you eat every day in your fatigue diary (tip 1).
- f. Speak to your nurse/dietician if you're finding it difficult to eat well or drink enough.

6. Aim to keep on top of pain – pain can cause fatigue

- a. Acute and chronic pain are managed very differently so speak with your doctor/ physiotherapist about what is best for you.
- b. Some medications can cause nerve pain. Talk to your doctor about any side effects and your medication.
- c. Other therapies such as relaxation can help relieve pain.

7. Plan, prioritise, and pace activity

- a. Plan an activity/rest programme that enables you to do things you want to do most, with time to rest.
- b. Doing things for yourself is very important however some days you may not be able to do everything. Make a list of activities you need to complete throughout the day and decide what is most important for you. Ask for help from family and friends to complete other activities, for example, ask someone to

drive you to your appointments or to do your laundry once a week. Remember to talk to your family and friends about cancer related fatigue so they understand how you are feeling.

- c. Be realistic with what you would like to achieve in a day. Some people like to use the image of a battery as their energy supply. If you're feeling fatigued your battery might be running at 50% which means you have that amount of energy to get through your day. At the start of the day after getting up, having a shower and eating breakfast you may have drained your battery to 10%. If you don't stop and do something to recharge your battery (eg. take a nap, watch TV, read a book) then your battery may completely drain. This image can help plan how much is realistic to help make the energy last until the evening. Include rests after activities that use up a lot of energy.
- d. Use your fatigue diary (tip 1) to help you plan activities for times when you have more energy.

8. Manage fatigue at work or school - you may find that you can't continue working or going to school due to fatigue. Speak with your employer/school who may be able to make adjustments such as;

- a. Change hours so you can travel to and from work/school at less busy times.
- b. Find a parking space near to your work.
- c. Take short breaks regularly.
- d. Work/study from home if possible.
- e. Find lighter work/duties.

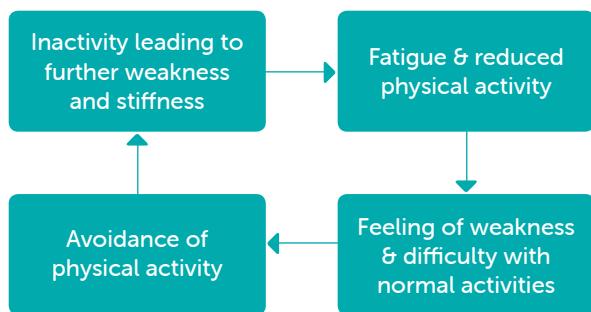
9. Keep a normal sleep routine, even if you feel like sleeping all the time (please refer to LBC Sleep Factsheet or Sleeping Well Webinar for more information).

- a. Wake up and go to bed at the same time every day.
- b. Reserve your bed for sleeping only.
- c. Don't sleep for long periods during the day but have a daytime nap (of 30 minutes or less).
- d. Exercise regularly (tip 10) which can help you sleep better in the long term.
- e. If you wake up during the night and are worrying about things, write them down in a worry book (or in your diary) to address the next day.



10. Exercise

- It is extremely important to remain active and factor this into your daily routine so your energy levels will improve.
- Tell your doctor before you start exercising; they can refer you to a physiotherapist if need be.
- Start off slow, don't over exert yourself and listen to your body.
- It is important to exercise regularly – it is better to do a little bit regularly rather than a lot infrequently. Try not to exercise too late in the evening.
- Set some goals, this will motivate you further to complete activity.



There has been a lot of research that shows fatigue can be managed well with regular exercise. Exercise is important to improve fitness, strength, and flexibility and also has a positive effect on emotional well-being and quality of life.

Exercise doesn't necessarily mean hard physical activity. The amount and type of activity will be different for everyone and will depend on your diagnosis, treatment and current blood results. Walking up the stairs may be enough exercise for one person whereas a 30 minute bike ride might be more appropriate for someone else. Speak with your doctor, nurse or physiotherapist about an exercise programme that would be good for you.

Cardiovascular

- Walking
- Riding your bike
- Skipping
- Dancing
- Treadmill

Strength

- Climbing stairs
- Carrying groceries
- Sit to stand exercises
- Swiss ball exercises
- Resistance bands
- Weights

Flexibility & Balance

- Stretching
- Yoga
- Tai Chi
- Wobble board

QUESTIONS & NOTES



Important information available online

For more information and to download other fact sheets, see our website
www.leukaemia.org.nz



If you would like to get in touch:

Call: 0800 15 10 15

Email: info@leukaemia.org.nz

Visit: www.leukaemia.org.nz

Mail: PO Box 99182, Newmarket, Auckland 1149

Post: PO Box 55102, Newmarket, Auckland 1149
Or visit one of our Support Services offices in Auckland, Hamilton, Wellington, Christchurch or Dunedin