

Coping with cancer fatigue

Fatigue is a feeling of severe tiredness experienced by many people who have cancer and its treatment (chemotherapy, radiotherapy, hormone therapy and, sometimes, surgery). This information sheet answers common questions about fatigue caused by cancer and cancer treatment.

What is cancer fatigue?

Cancer fatigue means tiredness and lack of energy. Fatigue is the most common side effect of cancer and its treatment.

Cancer fatigue is very different from everyday tiredness. It can happen suddenly. Unlike everyday tiredness, it is not necessarily brought on by exercise or a long day's activity. Resting does not always help relieve the fatigue. It can go on for weeks, months or even years after you finish treatment. Doctors call this 'chronic fatigue' – long-lasting tiredness. Most people will regain their normal energy levels between six months and a year after their treatment ends. For some people it can take longer.

Fatigue can be overwhelming and frustrating. It can touch many parts of your life.

How does it feel?

Different people have different symptoms. People with cancer fatigue describe feeling weak, exhausted, sleepy, drowsy, weary, confused or impatient. Some describe it as a 'whole body experience' and say they 'just cannot move'. Others have tired or

sore limbs and feel breathless, even after only a little activity.

For many people, cancer fatigue is unlike anything they have experienced. It can often be difficult to describe and hard for others to understand.

How does it affect you?

Many people with cancer say fatigue is the most difficult of all side effects from their cancer and its treatment. Fatigue can affect how you think as well as how you feel.

- You may need more sleep or find it hard to sleep.
- You may have physical, emotional and/or mental exhaustion.
- Your body, especially your arms and legs, may feel heavy.
- You may have less desire to do normal things, like eating, chatting with friends and family or shopping.
- You may find it hard to concentrate or think clearly.
- You may not feel like sex (loss of libido).
- Everything can seem like an effort. You may become low in mood because of these feelings.

Some people can even get depressed. If you have continued feelings of sadness, have trouble getting up in the morning or don't feel like doing things that you used to enjoy, talk to your doctor. You may have depression, and counselling or medication may help you.

'I had no idea that I would still be feeling tired five months after finishing treatment ... I didn't know

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how to make it better and I was scared that's how it would be: that I wouldn't go back to normal, that I would never go back to having energy again.' (Georgina)

What causes it?

Fatigue during treatment can be caused by the side effects from cancer treatments such as:

- chemotherapy
- radiotherapy
- surgery
- bone marrow transplants
- biological therapies
- hormone therapies.

A common side effect from some of these treatments is having too few red blood cells (anaemia). Anaemia means there are fewer red blood cells to carry oxygen through your body.

The cancer itself can also cause fatigue. Some cancer tumours produce toxins. These can cause tiredness or stop cells making important minerals in our body, such as potassium and calcium. When our levels of such minerals get too low it affects our muscles and may cause weakness and tiredness. Cancer treatment can sometimes affect hormone levels, which can also reduce energy levels.

Other things related to your illness can make you feel tired: not eating well, pain, not sleeping well, feeling stressed, having depression, coping with infections, some drugs, and not exercising.

You may also be affected by other health problems; side effects from pain-relieving drugs, steroids, sleeping tablets or antidepressants; and emotional problems.

Doctors are still trying to find out the exact causes and ways of managing fatigue after treatment finishes.

How do people cope?

If you feel fatigued, be honest about it – with yourself and others. Check with your doctor whether there is a medical treatment that could help you.

Try these ideas.

- Set small, manageable goals.
- When you plan your day, include rest times. Keep a record of how you feel during the day. For example, if you notice that you are especially tired in the morning, plan to rest at this time.
- Have several short naps or breaks, rather than one long rest period.
- Don't do more than you comfortably can. Stop before you get tired or recognise the warning signs for next time.
- Eat as well as you can and drink plenty of fluids. Some people find that a diet with lots of fruit and vegetables and grain-based foods (like pasta and rice) gives them a feeling of energy. Others might get the same feeling from having more meat in their diet. A dietitian will be able to help if you want to change your eating habits.
- Smoking reduces your energy. If you smoke, talk to your doctor or the Quitline on 13 7848 about stopping.
- Limit the amount of alcohol you drink as it can cause tiredness and energy loss.
- Exercise if you can. Exercise will keep you stronger and improve your sense of wellbeing. If you are not used to exercise, you could start a gentle walking program, beginning with five to 10 minutes at a time. Gradually increase this

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time as you feel able. You could also try other light exercise such as stretching.

- If you have been used to more vigorous or strenuous exercise, try easier or shorter versions of activities you enjoy. For example, instead of running, try yoga or t'ai chi. Building up to 30 minutes of active exercise five to six days per week can help with fatigue.
- Try to do things that make you happy. The joy you get from laughing with friends or playing with your dog may give you a boost.
- Listening to music, reading and meditating are not physically tiring and may help you to relax.
- Do the things that you need and want to do. If you have people around you who are able and willing, let them take on some of your usual activities.
- Limit the number of visitors you have if you need to.
- Avoid stress where possible: relaxation techniques and exercise can help to reduce unavoidable stresses.
- Keep a journal of your energy levels and activities.
- Call the Cancer Council Helpline on **13 11 20** to speak with a Cancer Connect volunteer, who can share their story of how they coped.
- Join a Cancer Support Group. You may also find it helps to speak with one of our cancer nurses, who can suggest strategies. Talking about your feelings can ease the burden of fatigue, and you can hear how other people in similar situations have managed.

Tips for managing daily activities

Contact your local council and ask about the practical support and services they offer. (Use the White Pages, business section, under the council's name.) These include meals on wheels; home cleaning, maintenance and gardening; day care for adults and children; pet walking and grooming; and volunteer visitors. Some of these services are free and some are low cost.

The social worker at your hospital can advise you about other services. A physiotherapist or occupational therapist can also help.

In the bathroom

- Sit down to bathe and dry yourself.
- Long, hot showers and baths could make you feel more tired.
- Use a shower/bath organiser placed where you can easily reach it.
- Install rails and handles where you need them, for example, in the shower and near the toilet.
- Use extension handles on sponges and brushes.
- Install a raised seat on the toilet.

Dressing

- Plan what you will wear and have your clothes ready before dressing.
- Sit down to dress and try to avoid bending from a standing position.
- Wear comfortable clothes and low-heeled shoes.

Housework and gardening

- See if your local council can provide a house cleaner or gardener.
- Let family and friends help with tasks where possible.

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- Schedule household tasks over the week (e.g. washing one day, vacuuming the next) so you don't do too much on one day. Lower your standards for a while!
- Where you can, sit to do housework and gardening.

Shopping

- Use a shopping trolley rather than a basket.
- Have your groceries delivered. You may be able to order from home.
- Ask for help. Use shops where the staff are considerate and will carry your bags and boxes to the car.
- Shop at less busy times (evenings or early in the morning).
- Organise your list by aisle if you know your supermarket well.

Meal preparation

- Use frozen foods.
- Make meals you don't need to toil over. These are all healthy and easy to prepare: tinned sardines, tuna and salmon; salad; omelettes and scrambled eggs; baked potatoes; steamed vegetables; grilled lean chops; vegetable stir fries.
- Rearrange things so you don't have to bend or reach. Store frequently used saucepans and utensils on a bench rather than in a cupboard.
- Order take-away food sometimes if you can afford it. Accept offers of meals with friends and family.
- Soak dishes instead of scrubbing and let dishes air dry. Wash up after each meal so the dishes don't build up.
- If you're making a soup or pasta sauce, make extra portions that you can freeze.

Child care

- Encourage games where you can sit: drawing pictures, playing board games, reading and computer games.
- Have children climb onto your lap instead of being lifted.
- Feed children at their own level (such as at a play table) if they're too small to climb onto a chair at the dining/kitchen table.
- Arrange child care so that you have regular rest times on your own.

At work

- If you are finding your usual duties difficult, consider talking with your employer about whether your duties or hours can be modified.
- If the fatigue is making working difficult, consider taking leave or reducing your hours for a short term.
- If you can, plan to work most intensively when you will feel most energetic and plan short rest periods for when you are likely to be tired.
- If your work involves a lot of bending and movement, see if it is possible to change your duties for the short term.
- Reduce the amount of bending and reaching you have to do by placing frequently used items in easy reach. Bend from your knees, not your back.
- Use a cart to move larger items.
- Delegate if you can: ask others to do things that you find difficult to do.
- If you have problems with employment or your employer because of your cancer or anything related to your cancer treatment, be aware of your rights. Visit www.cancervic.org.au or call the Cancer Council Helpline on **13 11 20** for a copy of *Cancer: Legal Rights and Responsibilities*.

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Leisure

- Going out with a friend is easier than going out alone.
- Do things gradually at first; aim for major activities only when your fatigue is lessening.
- Plan rest times between activities.
- Try not to get overtired.

Is rest always best?

Friends and family may advise you to 'take it easy' and 'get plenty of rest'. But staying in bed for a long time can cause you to feel even more tired. If you rest for a long time, your muscles will weaken and you will find it harder to be active when you want to. So being as active as you can, without making the fatigue worse, is your best approach.

- Talk to your doctor or nurse about how much bed rest and exercise they would recommend.
- Other people may not understand that rest does not make your fatigue go away. It may help to explain to them that fatigue is different from normal tiredness.

When should I speak to the doctor or nurse?

Speak to your doctor before starting an exercise program. Discuss other ways of managing the fatigue and living as normal a life as possible.

Tell your doctor or nurse if:

- you get dizzy
- you feel a loss of balance when walking or getting out of bed or a chair
- you fall or hurt yourself
- your body aches
- you lack energy
- you find it hard to wake up

- you have been too tired to get out of bed for 24 hours
- you have any breathing problems
- your fatigue becomes worse
- you feel confused or cannot think clearly
- you have trouble sleeping.

When will the fatigue get better?

You may find that the fatigue begins to lift when your cancer treatment ends. However, some people are fatigued for some time after treatment ends. Sometimes the fatigue will lift, then return again.

You may need to be patient if your recovery is not as fast as you wish.

If your fatigue is worrying you, talk to your doctor or nurse. They may be able to estimate how long the fatigue could last.

Contact the Cancer Council Helpline on **13 11 20** (cost of a local call). This is a confidential service staffed by cancer nurses. Information is available in languages other than English.

Reviewed by Annie Angle, cancer nurse (Dip. Oncology Nursing, Royal Marsden, London) November 2010.

