

Tiredness or cancer fatigue

There is more information on bladder cancer and its treatment on our website at actionbladdercanceruk.org

Severe tiredness or fatigue is experienced by many people who have bladder cancer, yet it is rarely talked about. The feeling of physical, mental and emotional exhaustion is probably completely different from anything you felt before the cancer started (see Box below ①).

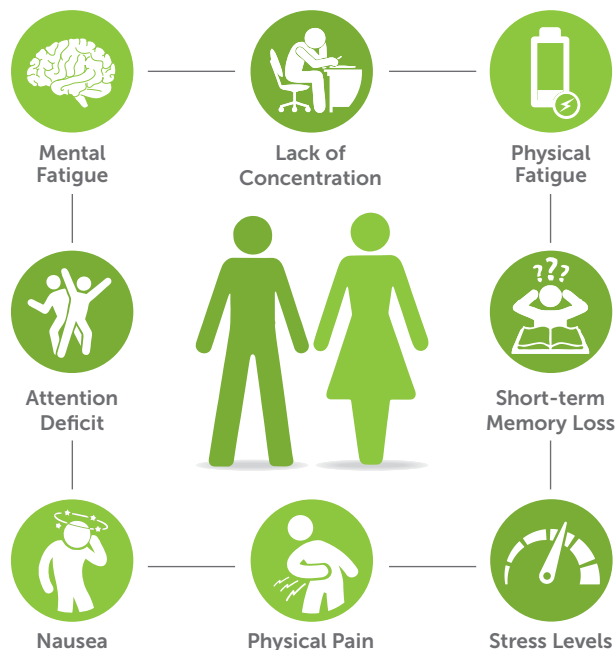
How cancer fatigue can affect you

- A feeling of tiredness that doesn't go away or get better
- Feeling more tired than usual during or after an activity
- Feeling tired even though you've not done anything
- Being less concerned about your appearance
- A feeling of heaviness in your arms and legs
- Having no energy
- Feeling weak
- Resting or sleeping doesn't help
- Spending more time in bed and/or asleep
- Staying in bed for more than 24 hours
- Becoming confused

①

Fatigue linked to cancer is known as cancer-related fatigue, or just cancer fatigue. There's likely to be more than one cause. The cancer itself, the effects of surgery and some treatments can change the way the body works (see Box below ②). And sleep problems, worry, stress, pain, poor eating, not drinking enough liquids and lack of exercise can make it worse. You can feel the effects of fatigue at any time – before diagnosis, after surgery, during maintenance treatment or during recovery.

Cancer fatigue affects people differently



Before diagnosis

Fatigue can be one of the symptoms of having cancer which some people experience even before they are diagnosed. If you are chronically tired for no obvious reason, go and see your GP.

Effects in the body that can lead to fatigue

- Cancer cells drain energy from the body as they are very active. The resulting tiredness can be a symptom in people with advanced cancer
- Your body has to work hard to clear away damaged cells and tissue that build up as a result of treatment
- Having cancer can disrupt the way healthy parts of the body function, leading to tiredness

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After surgery

You may feel exhausted after a TURBT or partial or radical cystectomy. The reasons may be a mix of sleeplessness and anxiety beforehand, the disruption of normal routine, blood loss during the surgery, overdoing it too soon, pain or discomfort, and stress. The feeling may persist for weeks or, in some cases, months. If you've had a cystectomy, for example, your energy levels probably won't start to return until about 6 weeks after the surgery and won't reach a more usual level for 3 months. Your body is trying to heal the 'raw' area inside your abdomen and needs to use energy to do this. It might take 6 months until you feel more like you are 'back to normal'.

Your medical team will talk to you about what to expect after surgery, and how to get back to your usual daily activities. Plan a slow and steady increase in your activities in the timeframe they suggest. Walking is strongly recommended.

During treatment

Fatigue is very common during treatment for bladder cancer as the body deals with the treatment's effects on cancer cells and healthy cells. The effects of treatment, such as nausea and vomiting, can also mean you don't eat properly, and this can also contribute to fatigue.

Any of the treatments for bladder cancer – BCG immunotherapy, radiotherapy or chemotherapy – can leave you feeling wiped out. And you may feel worse if you've lost your appetite or have been vomiting because of treatment.

BCG immunotherapy aims to trigger the body's immune system to cause a chain of events that end up attacking the bladder cancer cells. Fatigue is very common and can be long lasting, though sometimes doctors are unaware of this effect. Having to cope with an irritable bladder can contribute to exhaustion, especially if it's affecting your usual sleep and rest.

Radiotherapy You may find yourself feeling more and more tired as your radiotherapy goes on. The radiation treatment itself can make you tired, and this can be worsened by having to travel to the hospital for appointments. The effects may last for some months after the last treatment.

Chemotherapy Many chemotherapy drugs temporarily stop cells from dividing, especially the cells that divide quickly, such as white and red blood cells. The result is that there are fewer white and red blood cells, making you feel very tired. The worst time is usually midway between treatments, though some people feel worse straight afterwards.

During recovery

Some people have long lasting fatigue that persists into recovery periods. It can be frustrating, and might lead to anxiety about work or caring responsibilities and the future.

Coping with fatigue

Talk to your medical team Always talk to your medical team if fatigue is affecting your life. They may be able to:

- tell you whether medications or other medical conditions could be causing or contributing to the fatigue
- give you an exercise programme
- teach you some relaxation exercises
- advise you to change your diet or drink more fluids

- prescribe or recommend some medications or nutritional supplements that might help
- arrange for you to see specialist, such as an occupational therapist or nutritionist

Helping yourself The exhaustion may have caught you by surprise, and you may feel that you should be doing more. Try not to expect too much of yourself, and give yourself time to get your energy back. Simple changes to daily life can help.

Having cancer fatigue can feel like having your battery drained all the time



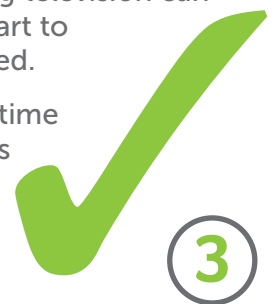
- Plan, pace yourself and prioritise – it's helpful to think of your body like a mobile phone battery. If it's not fully charged, it will quickly drain down. Plan to do activities when your batteries are full – the times and days when you have more energy. Pace yourself by slowing down and not trying to do everything at once.
- Write down how you're feeling in a diary – it might help with your planning if there's a pattern to how you feel
- Set small goals that you know will make you feel like you've achieved something
- Be open about how you're feeling and let other people help you. Ask for help if no one offers
- Improve your chances of a restful sleep by following some simple advice (see Box 3)
- Sit down to do activities such as washing up, ironing, and cooking if you can. Take rest breaks
- Treat yourself – so something you enjoy when you have energy, rather than chores. And schedule in some rest or a rest day after activity
- Learn to listen to your body and be aware of how you're feeling – is it time to take a break?

Joining a support group or learning stress management techniques may also help you feel better. There's also evidence that simple activities like sitting beside a lake, gentle gardening can help reduce cancer fatigue.

You may not feel like it, but gentle exercise can also help reduce fatigue. Exercising can make you feel less tired and can also help you sleep.

A better night's sleep

- Try to keep to a normal routine, going to bed and getting up at the same time is possible – and try to avoid lying in, even if you've had a bad night
- Having a relaxing routine before bed can help – have a warm bath or shower, read or listen to relaxing music or sounds
- Try to keep your bedroom dark, comfortable and quiet
- Try having a warm milky drink before you go to bed
- Try not to have a large meals or caffeinated drinks in the evening
- Write down things that are on your mind so you can ask someone about them the next day
- If you can't get to sleep straightaway or after waking, get up and go to another room. Do something that's absorbing but not mentally stimulating. A jigsaw is ideal, but reading or watching television can also help. When you start to feel tired, go back to bed.
- Some people find day-time naps helpful, but others find they affect their sleep a night. Try to work to which type of person you are.





More information

As well as information about bladder cancer and treatments, our website has other information sheets that you might find helpful. You can also find your nearest bladder cancer patient support group.

Other charities have information on fatigue that may be helpful, too.

- **Cancer Research UK** at www.cancerresearchuk.org/about-cancer/coping/physically/fatigue
- **Macmillan Cancer Support** at www.macmillan.org.uk/information-and-support/coping/side-effects-and-symptoms/tiredness

They've also produced a short film featuring Denton, who describes how he coped with fatigue resulting from treatment for prostate cancer at www.youtube.com/watch?v=JMApRzwXFec