

ovacome..
ovarian cancer

Managing fatigue



Ovacome is a national charity providing support and information to anyone affected by ovarian cancer.

We run a free telephone and email support line and work to raise awareness and give a voice to all those affected by ovarian cancer.

This booklet is part of a series giving clinical information about ovarian cancer.

It is for people who are experiencing fatigue and would like to know more about its management.



Managing fatigue

Fatigue is common in people with cancer. It may be a symptom of your cancer, or it can be a side effect of your treatment.

Fatigue is a tiredness that exhausts you, leaving you with little energy and does not necessarily improve with rest. It can affect you mentally and emotionally as well as physically. People often describe cancer related fatigue as tiredness in your bones, that may not have a pattern and can come and go from day to day.

There are ways of managing fatigue and making changes in your life that save your energy and help you to feel stronger.

What are the causes?

Fatigue can sometimes begin from the day of diagnosis. It can be part of the overwhelming experience of hearing you have cancer. Physical activity levels can drop as you are thrown out of your routine, and this may trigger the early stages of fatigue.

The cancer itself can cause fatigue. It can use up your energy and make you feel less like eating and being active, which then makes fatigue worse.

Cancer and its treatment can cause your bone marrow to make fewer red blood cells, these carry oxygen around the body. This may result in anaemia which can cause fatigue. Your doctor may prescribe iron pills which can help, or you may need a blood transfusion. This can be done as an outpatient or with an overnight stay. A transfusion takes six to nine hours.

Cancer may also prevent your body making chemicals such as potassium and calcium. These keep your muscles working properly, including your heart. If you don't have enough of these chemicals, then you will feel tired.

The cancer may make fluid, called ascites, which can fill your abdomen, making it harder to breathe. So, you may be using more energy but getting less oxygen into your body which will make you feel more tired.

Chemotherapy

Many people experience fatigue when they have chemotherapy. Your red blood cell level is most likely to drop between treatments, so it is common to have some fatigue at that time.

Platinum based chemotherapy, which is used to treat ovarian cancer, can cause anaemia. This can be helped using a drug called erythropoietin (EPO) which helps the bone marrow produce more red cells.

Travelling to hospital for your treatment and spending time there, is itself tiring and stressful. Feeling or being sick, having diarrhoea and not drinking enough fluids can also add to fatigue.

You are more likely to experience fatigue if you are having a combination of treatments, are elderly, have advanced cancer, are in pain or have depression.

Current research

Research into the causes of fatigue and how it develops suggests that inflammation and the body's immune system could be involved.

It is looking at how genes that control inflammation could be risk factors for long-term fatigue.

It has also been found that cancer can cause cells to release higher levels of cytokines which are chemicals that affect hormones and nerves and could be linked to fatigue.

Studies have found that physical activity seems to be the most successful way of managing and reducing fatigue. Exercise needs to be planned carefully to avoid peaks of energy followed by troughs of tiredness – which can increase fatigue.

Exercise that is tailored to your individual needs and circumstances is the most effective way of managing cancer related fatigue.

How is fatigue different from normal tiredness?

Fatigue has symptoms that are more serious than the tiredness we are all used to experiencing from time to time. It can stop you from taking part in your usual activities and enjoying your life.

You might want to stay in bed and not bother to do much.

It may be hard to get up in the morning and be hard to go to sleep at night.

You may feel sad and anxious and negative about yourself.

It can be hard to concentrate, even on talking with a friend or watching TV.

Your muscles may hurt so it may be difficult to go upstairs or walk far.

Everyday tasks can make you breathless.

Your heart rate can increase. It may be difficult to think properly and make decisions.

You could lose interest in activities you used to enjoy.

Having more sleep and rest doesn't always make it better.

Pain and fatigue

Pain can make fatigue worse so getting effective pain control could help. It is important to find a balance as strong painkillers such as morphine can themselves cause fatigue and make the pain worse.

Pain can be frightening and make you think your cancer is getting worse. Worrying about pain can cause anxiety and depression which will make you more tired.

Remember that pain can be a side effect of chemotherapy or nerves recovering from surgery and other treatment. This can arise a long time after your treatment has finished. Your pain may not be related to your cancer.

How long will fatigue last?

If your treatment is causing the fatigue, then you may start to feel better when it is finished. But it can take a long time, weeks, or months, or perhaps even longer to recover completely. Your fatigue may have been building even in the months leading up to your cancer diagnosis.

You may have had surgery as part of your treatment, so your body needs time and energy to heal and repair itself inside and outside.

Hormone treatments, which are often used as maintenance treatments for ovarian cancer, can cause fatigue as they block or reduce hormone levels in the body. The fatigue may lessen as treatment side effects settle down.

With the right support and intervention, you can recover from cancer related fatigue as your energy levels begin to improve.

How can I help myself?

Fatigue is sometimes overlooked. You may have other health problems or side effects to deal with and not recognise the fatigue developing. Your family and friends may not see it either and expect you to do more than you can.

Having fatigue means that some tasks may take you two or three times longer than they did before. Your own routines may be causing problems with fatigue such as sleeping too much in the day and not enough at night, having visitors or looking after children.

Other health issues can make fatigue worse, they may be breathing problems, heart problems, diabetes and being overweight.

Some strategies to try

Pacing is a key strategy to managing cancer related fatigue.

Get to know your energy levels and patterns so you can plan your activities and exercise when these are at their best, such as mornings or afternoons.

Try to set realistic expectations for each day or week. Spread your activities out over the week, so you can use your energy evenly.

Most importantly, don't suffer alone. Seek help from your medical team to get the support you need, especially if your mood is low and you are struggling emotionally. Sometimes it can be hard to describe how you are feeling.

Be kind and compassionate to yourself, without the need to always push through and get everything done. It may help to check how you are feeling each day and rate your fatigue levels from one to 10, to help you plan the day ahead.

Getting enough rest

Make sure you get enough rest. It is important to balance rest with activity which is also part of your recovery.

Have a rest after a period of activity. You may also need to rest after meals. Include times to rest when you plan your day.

You don't have to sleep but if you do, try to keep to short naps (no longer than 30 minutes and avoid these late in the day), so your night-time sleep is not reduced.

Try not to stand for too long, so sit down to do tasks if you can and sit down to take a shower.

Plan activities that allow you to sit down and go to places where you know you can be seated.

Ask for help and accept offers of help. Someone may be able to go shopping for you or take children to school. Tell your family including your children that you are very tired and need to rest.

Plan your sleep

Keep to a regular sleep routine. Don't sleep late in the day if you have had a bad night as this can disrupt your sleep pattern. Early in the evening, try turning off screens and devices that emit blue light.

Eat well

It is important to eat enough to give you the energy you need. If you are too tired to cook meals or have no one to help you, try eating little and often. Remember to include protein in your diet, your body needs this to repair itself after surgery and other treatments.

A dietitian can help you to plan your meals to ensure you are getting the nutrients you need. You can ask your clinical team or GP to be referred for this service.

Exercise!

Keeping a balance between resting and physical activity will help you to manage your fatigue. Inactivity weakens muscles and makes the fatigue worse while exercise will give you energy, help your appetite and improve your sleep.

You can ask to be referred to see a physiotherapist, or a cancer exercise specialist/personal trainer who will advise you about the best exercise for you and help you to plan activities that meet your needs and promote your recovery.

Start by moving around a little more often and slowly build it up. Do something you enjoy; this might be a gentle exercise routine or a short walk. On days when fatigue levels are high, try seated exercises or gentle stretching.

Developing a routine can help you to stick to your exercise programme. You could keep a diary of your exercise so you can see how you are progressing.

Try to avoid long periods of inactivity as this can make fatigue worse. Some physical activity, even just a little, can give you a sense of achievement and help your confidence.

Drink fluids when you exercise to make sure you don't get dehydrated. Speak to your doctor, nurse, or physiotherapist if you are planning to go on a more demanding exercise programme.

Mindfulness, meditation and breathing exercises

These techniques can help you to manage fatigue. They can help to restore you when you feel anxious and lacking energy. Just 10 minutes a day can bring about a sense of calm, leaving you feeling more in control.

What Ovacome members say about fatigue

- Pace yourself. You will have energy peaks and troughs so find a level you can maintain.
- Find ways of conserving your energy.
- Use ready prepared veg instead of chopping it up yourself.
- It can be hard to accept help if you have always been the care giver and provider. People want to help you, otherwise they feel helpless.
- If you find yourself saying "I should be doing..." stop right there.
- Accept help and rest when you need to, or it will take longer to recover.
- Find ways of keeping exercise in your life. It helps your mood and body.

Aids to help you

There is a range of aids designed to help people with limited strength and energy. These include perching stools, which support you while you are cooking and doing other household tasks, wheeled trolleys with trays so you don't have to carry items yourself and shower seats.

These are available after an assessment by an occupational therapist. They can advise you on managing your fatigue and recommend aids to help with your daily activities. You can be referred to this service at your treatment centre or by your GP. Aids are also available from the British Red Cross.

Commodes are also available. You can keep one downstairs to save you climbing your stairs just to use the toilet. Use a fabric throw to disguise it as a chair.

Useful links

www.nhs.uk/conditions/social-care-and-support-guide/care-services-equipment-and-care-homes/household-gadgets-and-equipment-to-make-life-easier

www.themobilityaidscentre.co.uk/living-aids/household

Download the Untire app here: www.untire.me

We welcome your feedback on this booklet. Please email ovacome@ovacome.org.uk or call 0800 008 7054. If you would like to discuss anything about ovarian cancer, please phone our support line on 0800 008 7054 Monday to Friday between 10am and 5pm. You can also visit our website at www.ovacome.org.uk. This is one of a series of information booklets produced by Ovacome. You can see them here: ovacome.org.uk/information.

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