

# COPING WITH FATIGUE (TIREDNESS)





**'I realised that the more I was doing nothing, the more tired and fatigued I was feeling. I'd end up feeling sorry for myself – it was a vicious circle.'**

Jane, diagnosed with colon cancer

# About this booklet

**This booklet is about coping with fatigue caused by cancer or its treatment (cancer-related fatigue). Fatigue means feeling very tired or exhausted all or most of the time. The tiredness is not helped by rest and can affect you physically and emotionally.**

This booklet is for anyone who has cancer-related fatigue. There is also information for carers, family members and friends.

This booklet explains the causes of cancer-related fatigue and ways of managing it. We hope it helps you deal with some of the questions or feelings you may have.

## How to use this booklet

The booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 3 to help you.

The booklet contains a lot of information. You may find it difficult to read all in one go if you are feeling tired. It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

This booklet is also available as an audiobook, if you prefer to listen to the information.

## Quotes

We have included quotes from people who have cancer-related fatigue which you may find helpful. This includes Jane, who is on the cover of this booklet.

Some quotes are from our Online Community ([macmillan.org.uk/community](https://www.macmillan.org.uk/community)). Others are from people who have chosen to share their story with us. To share your experience, visit [macmillan.org.uk/shareyourstory](https://www.macmillan.org.uk/shareyourstory)

## For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, Monday to Friday, 9am to 8pm, or visit [macmillan.org.uk](https://www.macmillan.org.uk)

If you would prefer to speak to us in another language, interpreters are available.

If you are deaf or hard of hearing, use textphone **0808 808 0121** or Text Relay.

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations. To order these visit [macmillan.org.uk/otherformats](https://www.macmillan.org.uk/otherformats) or call **0808 808 00 00**.

# Contents

Fatigue and its effects	5
Causes of fatigue	11
Help with fatigue	25
Managing your fatigue	29
Living with fatigue	39
Looking after someone with fatigue	51
Work and financial support	55
Further information	63



# FATIGUE AND ITS EFFECTS

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Fatigue and cancer 6

The effects of fatigue 8

# Fatigue and cancer

Fatigue is a feeling of tiredness or exhaustion. It is a very common problem for people with cancer.

As many as 9 out of 10 people with cancer (90%) may feel fatigued at some time. This is called cancer-related fatigue or CRF. The causes of CRF are not fully understood. It may be caused by the cancer itself or its symptoms. It can also be a side effect of treatment.

Fatigue can be especially difficult to deal with when you are already trying to cope with cancer. You may feel very tired or exhausted all or most of the time.

CRF is different from the tiredness that someone without cancer may get. People with cancer may get tired more quickly after less activity. Their fatigue may not be helped by rest or sleep. For most people, fatigue gets better after treatment finishes. But for some it may continue for months or sometimes years. Everyone is different and there is no way to know how long fatigue may last for each person.

It is important to tell your doctors and nurses about your fatigue and how it makes you feel. Be honest and don't say you feel fine if you do not. There may be things they can do to help. For example, it can help to treat the causes of fatigue, such as anaemia or sleeplessness (see pages 11 to 23).

There are also things you can do for yourself that may help you cope. For example, it can help to find ways to pace yourself through the day. Trying to stay physically active can also help. We have more information on living with fatigue and how you can best manage it (see pages 39 to 49).



# The effects of fatigue

Some people find their fatigue is very mild and it does not really affect their daily life. But for others, it is very disruptive.

The different levels of fatigue are described in our fatigue diary. The diary is attached to the inside of the back cover of this booklet.

Some of the more common effects of fatigue include:

- difficulty doing simple things, such as brushing your hair or getting dressed
- feeling you have no energy or strength
- difficulty concentrating and remembering things
- difficulty thinking, speaking or making decisions
- feeling breathless after light activity
- feeling dizzy or lightheaded
- difficulty sleeping (insomnia)
- losing interest in sex
- feeling low in mood and more emotional than usual.

Having one or more of these effects can affect your daily activities or social life. For example, finding it hard to concentrate may affect your work or studies. If you need to take time off or stop working because of fatigue, then it may start to affect you financially. See pages 48 to 49 and 56 to 61 to read more.

Fatigue can also affect your relationships. You may need to rest more, meaning you might spend less time with friends and family. Or you may avoid going out or being with friends because it makes you very tired.

Fatigue may also affect you if you are living with other health conditions. For example, people who have diabetes may already be coping with tiredness caused by the diabetes. But cancer-related fatigue may make this worse.

You may find our booklet **Diabetes and cancer treatment** helpful (see page 64).

There are things you can do to help manage fatigue (see pages 29 to 37). Getting help and support from your healthcare team may help prevent or relieve some of these effects (see page 27). It may also help improve your quality of life.

'It's really important to make time to rest, relax and revitalise. Know your body and don't battle it constantly.'

Ali

**'I still experience fatigue. But once I've pulled myself off the mattress in the morning, the exercise I do actually makes me feel more alive and prepared to take on whatever life throws at me that day.'**

**Jane**



# CAUSES OF FATIGUE

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What causes fatigue?

12

## What causes fatigue?

The cause of cancer-related fatigue (CRF) is not fully understood. There may be many reasons for it. These include:

- the cancer itself
- cancer treatments
- anaemia
- eating problems
- other health problems
- psychological effects of cancer.

You may feel tired before treatment starts because of the tests and scans you have had to diagnose the cancer. If you are older, have other health problems, or have more than one type of treatment, you are more likely to be affected by cancer-related fatigue.

'I think people really find fatigue difficult to understand. If I tell someone I'm in pain they kind of accept it, but if I tell someone I'm tired they just think "So what? I'm tired too".'

**Cat**

## The cancer itself

For some people, the cancer itself may cause fatigue.

This might be because of the symptoms of cancer. For example, parts of your body may be swollen because the cancer has caused a build-up of fluid. This can make them feel heavy and it can be difficult to move around.

You may feel tired because the cancer has reduced the number of red blood cells. Red blood cells are made in your bone marrow. They contain haemoglobin which carries oxygen to cells. If the haemoglobin level goes down and cells are not getting enough oxygen, you are likely to feel very tired. A reduced number of red blood cells is called anaemia (see pages 16 to 17).

Cancers that cause changes in hormone levels, such as breast or prostate cancer, may cause fatigue.

Cancer may also affect the levels of cytokines in the body. Cytokines are a type of protein made in the body. They help control some of the things that cells do. Studies show that cytokine levels can be higher in people with cancer-related fatigue than in people without it. This may cause some symptoms such as tiredness. But we still do not fully understand whether cytokines cause tiredness.

## Cancer treatments

Apart from treatment-related anaemia, doctors are still trying to find out exactly why cancer treatments cause fatigue. It is thought that fatigue may happen after having cancer treatment because:

- the body needs extra energy to repair and heal
- there is a build-up of chemicals as the cancer cells are destroyed
- the body's immune system is affected.

### Surgery

Many people feel tired after surgery and need to avoid doing too much for a while. This effect does not usually last long. However, some types of surgery may cause continuing problems with fatigue. For example, surgery to the stomach may cause problems with absorbing food. Not being able to absorb nutrients from food can affect your energy levels.

### Chemotherapy and radiotherapy

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells. It is often given in cycles a few weeks apart. Some people feel most fatigued in the first few days after chemotherapy. They then find it gets better for a while before the next cycle. The fatigue may increase with each treatment.

Radiotherapy is the use of high-energy rays to destroy cancer cells. Often, people feel more fatigued as the treatment goes on.

Fatigue caused by chemotherapy or radiotherapy usually improves after treatment, but sometimes it can become a long-term problem.

Sometimes these treatments may cause long term effects such as breathlessness or heart problems. These are likely to make you feel more tired. We have more information about long term effects. You may also find our booklet **Heart health and cancer treatment** helpful (see page 64).

Many people find their normal levels of energy return within 6 to 12 months of the treatment finishing. However, some people find they still feel tired and have low energy levels a year or so later. Sometimes, tiredness can continue for 2 years or more, although this is much less common.

### **Hormonal therapies**

Hormonal therapies can stop or slow down the growth of some cancer cells. Some types of hormone therapy reduce the levels of particular hormones in the body. Other types prevent the hormones being absorbed by cancer cells. Hormonal therapy is often given for several years. Some hormonal therapies can cause fatigue.

### **Targeted (biological) therapies**

Targeted therapy uses substances that target the growth of cancer cells. Some targeted therapies can cause fatigue.

## Anaemia

Anaemia is a possible cause of cancer-related fatigue.

Anaemia is caused by not having enough haemoglobin (Hb) in the blood. Haemoglobin is found in red blood cells. It carries oxygen around the body. As red blood cells move around the body, they carry oxygen to all the body's cells. This gives the body energy.

If the number of red blood cells is low, there is less haemoglobin. This means less oxygen reaches the cells. If the level of haemoglobin in the blood drops below normal, you may feel tired and have less energy.

Your doctors will regularly check your blood cell levels.

If you have anaemia, you may also find that you:

- are breathless
- feel dizzy and light-headed.

People with heart problems such as angina may find these problems get worse. Or they may have more chest pain than usual if they are anaemic.

You may find our booklet **Heart health and cancer treatment** helpful (see page 64).

## Causes of anaemia

Anaemia can be caused by different things. It may be caused by the cancer itself. This is because some cancers cause fewer red blood cells to be made in the bone marrow. Other cancers may cause bleeding. A loss of blood may lead to anaemia.

Chemotherapy can cause anaemia. It reduces the number of red blood cells you make.

Radiotherapy can also cause anaemia if it is given to an area of the body that contains bone marrow. Bone marrow is found inside our bones, mainly in the hip bone and the breast bone (sternum). It is where red blood cells are made. If you have radiotherapy for breast cancer, for example, the radiotherapy will affect the breast bone.

If you are anaemic, your doctor may be able to give you treatment that can help. The treatment for anaemia depends on the cause. The main treatment is a blood transfusion. This is a drip (transfusion) of red blood cells given directly into the bloodstream. This can quickly increase the number of red blood cells in the body.

If you are having chemotherapy, you may be offered a drug called erythropoietin, which can help increase the number of red blood cells in the body.

## Eating problems

Our bodies get energy from the food we eat. Fatigue can happen if the body does not get enough food, or if there are changes to the way the body is able to use the food. If you have cancer, this can happen because:

- you cannot eat the same amount of food as you normally would
- your body needs more energy than it did before
- your body may not be able to absorb and use all the nutrients from the food.

You may lose weight even if you are eating a lot, because of the effect of the cancer on the body.

If you feel sick (nausea), you may eat less. This could mean that you do not get enough energy from food. If you are sick (vomit), your body does not absorb the food and its nutrients. This can make you feel weak and tired, and you may also become dehydrated.

If you have nausea or vomiting, your doctor can prescribe anti-sickness (anti-emetic) drugs, which usually help. Some anti-sickness drugs can cause tiredness and may make you feel drowsy. However, it is important to keep taking them. Let your doctor know if this is a problem.

If you cannot take anti-sickness tablets or keep them down due to vomiting, speak to your doctor or nurse. There are other ways of taking anti-sickness medicines. Your healthcare team can discuss this with you.

Chemotherapy can cause changes in appetite and taste, which may cause you to eat less. There are things you can try that may help with this. Your doctor, nurse or hospital dietitian may be able to help.

You may find that you use all your energy cooking and then feel too tired to eat. It can help to ask someone else to prepare food for you, or buy some ready-made meals. Some organisations deliver ready-made meals to your home. You can also contact your council's social services department to find out if you qualify for their 'meals on wheels' service.

You could try having regular, small amounts of food or snacks, rather than a big meal. If you do not feel like eating, you could try ready-made, high-calorie drinks. These are available from any chemist. Some are available on prescription.

Unflavoured high-energy powders can add calories to food without making your portion any bigger. These are also available on prescription.

We have more information about eating problems and coping with eating difficulties caused by cancer or its treatment (see page 64 for ways to order).

You may find our booklets **Healthy eating and cancer**, **The building up diet** and **Recipes for people affected by cancer** helpful. Some of these resources are also available as audiobooks if you find listening easier than reading when you are tired.

## Pain and other cancer symptoms

Many people with cancer do not have pain. But pain can cause fatigue. The best way to deal with fatigue caused by pain is to manage the pain.

If you are in pain, talk your GP, cancer doctor or specialist nurse about getting some painkillers to help with this. Some painkillers can make you feel drowsy or sleepy.

Some people find that complementary therapies such as acupuncture and relaxation help their pain.

We have more information in our booklet **Managing cancer pain** (see page 64).

## Other health conditions

Other health conditions like diabetes, heart problems or low thyroid function can also cause fatigue. Having a cancer diagnosis and other health conditions may make the fatigue worse.

Some medicines for other health conditions can also make you feel tired.

We have more information about diabetes and cancer online and in our booklet **Diabetes and cancer treatment** (see page 64).



## Psychological effects of cancer

Fatigue can be made worse by:

- anxiety
- depression
- stress and tension
- a poor sleeping pattern.

It is common for people to have anxiety or depression when they are first diagnosed with cancer. However, these feelings generally get easier to manage as you come to terms with what has happened.

You may find it helpful to discuss how you feel with your partner, a family member or close friend. Some people find it helpful to talk to other people at a local support group, or join an internet support group.

Macmillan's Online Community is a place you can talk to others who understand what you are going through. Visit [macmillan.org.uk/community](https://www.macmillan.org.uk/community)

If you find that your mood is low most of the time, you may have depression. If you have depression, your GP will discuss possible treatments with you. They can refer you to a counsellor and prescribe medicines to help if necessary.

## Loss of muscle strength (deconditioning)

If you have fatigue, you may become less active over time. When your muscles are not being used regularly, they become weaker. This is called deconditioning.

Having weak muscles means you will find it very difficult and tiring to do even simple tasks. It may also mean you are more at risk of falling over.

It is understandable that you may not want to do very much when you are dealing with cancer and its treatment. But staying active is the best way to keep your muscle strength and build up your energy.

You could start by sitting up in a chair rather than lying down in bed while you are recovering. Gradually build up to walking short distances around the house. Talk to your cancer doctor, specialist nurse or GP about being referred to a physiotherapist. They can help you with an exercise programme to build muscle strength safely.

We have more information in our booklet **Physical activity and cancer** (see page 64).

'I asked my nurse for some advice for getting through the chemo. She told me to sleep when you are tired but do small spells of activity often. So after every meal I took Laurel and Hardy (my chemo pumps) for a walk around the ward. It turned out that I was doing about 2 miles a day.'

**Mike**



# HELP WITH FATIGUE

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Ways to manage fatigue

26

# Ways to manage fatigue

How fatigue is managed depends on what is causing it (see pages 11 to 23). It is important to talk about fatigue with your healthcare team. There may be ways to improve it.

Your doctor will check for any causes of fatigue that can be treated, such as anaemia. They may examine you and you may have some blood tests. They may also look at the medicines you are taking. This is to check whether they can make changes to them that might improve fatigue. For example, they may reduce the dose of a tablet that makes you sleepy.

## Drug treatments for fatigue

There are not any licensed drug treatments to help prevent or improve fatigue yet. Steroid drugs, such as dexamethasone, can sometimes be helpful. But they can have side effects, so you should talk to your doctor about the possible benefits and disadvantages.

Research into other drug treatments is ongoing. Your doctor or specialist nurse can give you information about any drug trials that may be suitable for you.

We have more information about trials in our booklet **Understanding cancer research trials (clinical trials)** – see page 64.

## Getting support

If you are finding it very difficult to cope with fatigue, it can help to explain any problems to your doctor or nurse.

Tell them about the activities you find difficult. These activities may be things like climbing stairs, cooking or bathing. Let them know if anything makes the fatigue better or worse. If you are keeping a fatigue diary, you can show it to your doctor or nurse. You can use the one attached to the inside of the back cover of this booklet.

Here are some questions you may like to ask:

- What could be causing my fatigue?
- Are there any treatments that may help?
- What can I do to help reduce my fatigue?
- Could my medicines be affecting my energy level?
- What help is available?

'My haematologist said, "It can take a year, it can take a couple of years, it can take a couple of months.". It was very open ended and not specific, because every person is completely different. It's not set in stone. That was a shock, I think.'

**Frances**



**'Exercise helps me deal with the fatigue. I experience a form of adrenaline rush which makes me feel awake.'**

**Jane**

# MANAGING YOUR FATIGUE

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Things you can do

30

# Things you can do

There are things you can try yourself to reduce your fatigue. Physical activity and changes to your diet can help with fatigue. Talk to your cancer doctor, specialist nurse or GP before you make any big changes. They will make sure what you are planning is suitable for you.

## Physical activity

There is good evidence that physical activity can help reduce the symptoms of fatigue. Being active may help:

- boost your appetite
- give you more energy
- improve sleep.

If you have not been very active in the past or for a long time, it is best to start slowly. Try to get a balance between being active and getting some rest.

Choose an activity or exercise that you enjoy, as you are more likely to keep doing it.

If you have fatigue, being active may not always be possible. Remember that some exercise is always better than no exercise. It might help to set some simple goals. This could be walking from the front door to the back door. But try to do a little more activity each time, if you can.

Before you start doing any physical activity or increase the amount you do, it is important to get advice from a healthcare professional.

Your cancer doctor, specialist nurse or GP can advise you on the type and amount of activity that is safe for you to do. They can also refer you to a physiotherapist who can help you with some exercises to build up strength and energy. Talk to them about any other medical conditions you have, such as high blood pressure, diabetes or lung problems. These may be affected by physical activity.

Specialist cancer physiotherapists may be available in some areas. They can help you set realistic goals to keep you active and manage any side effects of treatment. Your GP or cancer doctor can refer you.

The physiotherapist may refer you to an exercise programme. These are run by healthcare professionals or experienced fitness trainers. Many people find socialising with other people in a group enjoyable. Exercising as part of a group can also help you to stay motivated.

## Tips for keeping active

- Do not exercise if you feel unwell, are in pain or have any other symptoms that worry you, such as feeling breathless. If you feel unwell or have worrying symptoms, let your doctor know.
- It is helpful to set yourself some simple achievable goals. Try not to do too much too soon.
- Plan some activity into your day. For example, walk to the shops instead of driving, if you can.
- Try some regular, light exercise, such as walking, and simple strengthening exercises.
- Do something you enjoy, such as gardening.

We have more information about physical activity online and in our booklet **Physical activity and cancer treatment** (see page 64).

## Healthy diet and weight

Eating well and keeping to a healthy weight can help you maintain or regain your strength. It can also give you more energy.

Your GP can advise you and give you information on your ideal weight. Eating a healthy diet and keeping to a healthy weight reduces the risk of heart problems, diabetes and developing some cancers.

It can help to:

- keep a diary of what and when you eat – this can help you see if you have more energy after certain meals
- drink plenty of fluids
- try different foods or eat foods that taste best to you if you have taste changes, until things improve
- ask your doctor to refer you to a dietitian – they can give you helpful ideas.

## Sleep

Even though your fatigue may make you feel like sleeping all the time, try to keep to a normal sleep routine.

Good-quality sleep may help with fatigue, as well as reduce your need to sleep during the day.

## Tips for a better night's sleep

- Go to bed and get up at about the same time every day.
- Try not to sleep late into the day after a sleepless night, as this can lead to a disrupted sleep pattern.
- Try to do gentle exercise like walking, as this can help you feel naturally tired and ready for sleep.
- Keep your mind occupied with activities like reading, games or puzzles. This can also help you feel naturally ready to sleep.
- Be aware of how naps affect you. Some people find that daytime naps help them sleep better at night, while others sleep less well after them.

We have more information about sleep (see page 64 to order)





Practising relaxation techniques

## Complementary therapies

There are different complementary therapies that may help with fatigue, such as:

- relaxation
- massage therapy
- yoga.

Many people feel that complementary therapies are supportive and can help you feel more in control of your health.

Some complementary therapies have been researched. But for other therapies, the evidence is based on people's personal accounts (anecdotal) rather than on facts.

Some of these therapies may be available on the NHS. Your GP can give you more details. You may also be able to get them through a cancer support group. If you find a complementary therapist, make sure that they are properly qualified and registered.

Before you use a complementary therapy, talk to your specialist doctor or nurse. Some therapies may affect your cancer treatment.

We have more information about complementary therapies (see page 64 for ways to order).

## Emotional support

Dealing with fatigue all the time can be very difficult. Some people find it can affect their feelings. If you are finding it difficult to cope, it can help to talk to someone close to you, such as a family member or friend. Or you may prefer to talk to someone in your healthcare team.

### Counsellors

If you feel anxious or depressed, you may find counselling helpful. Counsellors are trained to listen. They can help you deal with difficult emotions.

Many hospitals have counsellors or staff who are specially trained to provide emotional support to people affected by cancer. Your cancer doctor or specialist nurse can tell you what services are available. They can also refer you. Some GPs also have counsellors in their practice, or they can refer you to one.

If you would like to find out more about counselling, our cancer support specialists can tell you more about services in your area. Not all counselling services are available on the NHS.

### Support groups

Some people find it helps to talk to other people with fatigue. You may find talking to other people at the hospital helpful, or you could join a local support group.

Most areas in the UK have cancer support groups. They are sometimes led by a healthcare professional. Other members of the group may be in a similar position to you. Some support groups have counsellors.

Some people find groups helpful and make close relationships with other members. But if you try a group and it is not right for you, you do not have to go back.

## Online support

Many people get support on the internet. Online support groups for people affected by cancer include:

- social networking sites
- forums
- chat rooms
- blogs.

You can use these to share your experience. You can also ask questions, and get and give advice based on your experience. Our Online Community is a social networking site where you can talk to people, write blogs, make friends and join support groups. Visit [macmillan.org.uk/community](https://www.macmillan.org.uk/community)

'At times it can be incredibly frustrating not to have the energy or the physical strength to do something that I would love to do – whether that's going for a walk or doing some work. It is important to have plans and yet also be realistic about what is possible. I try to concentrate on what I can do rather than what I can't.'

**Carol**



# LIVING WITH FATIGUE

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Planning ahead	40
Managing everyday activities	42
Coping with fatigue at work	48

# Planning ahead

If you have fatigue, planning ahead can help. You could try planning your day so that you have energy to do the things you want to do most. It may help to think about whether there are any activities you are prepared to stop for a while, until you can do them again.

Writing down your energy levels will help you see the days and times when you have more energy. But you may not be able to do everything you used to do.

You can use a fatigue diary to keep a record of your fatigue. Write down the times when you feel your best and when you feel most tired. This may help you to plan your activities.

There is a fatigue diary for you to use attached to the inside of the back cover of this booklet.

Try to plan bigger tasks to fit in with the time of day when you feel least tired. Pace yourself, and plan enough rest and sleep periods. Plan a rest after activities. Some people also find that they need to rest after meals.

Short naps and rests can help, but try to balance them with some activity or exercise. Too much inactivity may lead to your muscles becoming weaker (see pages 22 to 23), which can make your fatigue worse. It is important that any rest during the day does not stop you from sleeping at night.

It is also important to plan around your treatment. Try to avoid anything energetic or stressful for 24 hours before and after your treatments. If you feel less well one day, it is okay to be less active and to rest more.

**'My advice would be to make life easy for yourself whenever possible. Get to bed at a decent hour and eat well. When you have a bit more energy, think about how to make life easier for yourself in the next week.'**

**Ruth, diagnosed with soft tissue sarcoma**



# Managing everyday activities

If you need help with things at home then you may be able to ask family, friends and neighbours. Building up a support network can make a big difference. If you always look like you are coping well with everything, your family and friends may not realise how much you need help. Or they may be waiting for you to ask for help.

You may find that some of the following suggestions help you deal with everyday tasks.

## Housekeeping

- Spread tasks out over the week. Try to do a little bit of housework each day rather than lots at one time.
- If possible, ask other people to do heavy work, such as gardening or taking the rubbish out.
- Sit down to do some tasks, if you can.
- If possible, employ a cleaner to help. This may be expensive. Depending on your circumstances, you may be able to get home help from social services.
- Use long-handled dusters, mops and dustpans where possible to avoid stretching and bending.

## Shopping

- If possible, go grocery shopping with a friend or family member for extra help.
- Use a delivery service. Most large supermarkets offer online shopping which can be delivered to your home.
- Make a list before you start, so you do not waste energy or time.
- Use a shopping trolley so you do not need to carry a heavy basket. A wheeled shopping bag may also be helpful when shopping and getting things home.
- Shop at less busy times.
- Ask shop staff for help packing and carrying groceries to the car.

'I have learnt to slow down and to focus on certain positive realistic goals for the day or week.'

**Carol**

## Preparing meals

- Try having ready-made meals or pre-cooked food when you are most tired.
- If you can, sit down while preparing meals.
- Prepare extra meals or double portions when you are feeling less tired and freeze them for when you need them.
- Try not to lift heavy pans when serving. Instead, take your plate to the cooker and put your food on it there.
- If you need to take things to the table, ask for help moving heavy items if you can. Or consider buying a wheeled trolley or tray.

## Washing and dressing

- Sit down in the bath rather than standing in a shower if you can, as this may help to use less energy.
- Sit down in the shower if you can, to avoid standing for too long. An occupational therapist may be able to get you a shower seat.
- Wear clothes that are easy to put on and take off. Sometimes wearing pyjamas is easier if you are not going out.
- Sit down when you are getting dressed.
- Consider wearing a towelling dressing gown after a shower or bath. This takes less energy than drying yourself with a towel.

## Occupational therapists

Occupational therapists look at practical ways of making a home safe, comfortable and easy to live in. They help people who have difficulty moving around or doing everyday tasks such as dressing, washing and cooking. They may be able to visit you at home to help you find ways to do things more easily.

Your cancer doctor, specialist nurse or GP can refer you to an occupational therapist.



## Childcare

If you have a family, you might find it difficult to look after them while coping with fatigue. This can be especially upsetting when you are unable to do your usual family activities. To make things a bit easier you could do the following:

- Explain to your children that you feel tired often and will not be able to do as much with them as before. You may be surprised at how well they respond.
- Plan activities with your children that you can do sitting down. For example, you could read, play board games or do a puzzle.
- Try to plan activities where there are places for you to sit down while the children play.
- Try to avoid carrying small children. Use a pram or pushchair instead.
- Try to involve your children in some household tasks.
- Ask for and accept help from family and friends. For example, someone may be able to take your children to and from school.
- If you can, get a babysitter for your children sometimes and do the things you need or want to do.

## Driving

Driving can be difficult and dangerous if you feel very tired. You may be less alert than normal, and less able to concentrate. Your reaction time will also be reduced.

You might find the following tips helpful:

- Do not drive if you feel very tired.
- If possible, ask a family member or friend to drive you.
- If you need to get to hospital appointments, ask your nurse or doctor if there is any hospital transport available so that you do not have to drive.
- If you have to drive, plan your trip for when you know you usually feel more alert. It may also help to avoid driving at times when the roads are busiest.
- If you need to make a long journey, plan to break it up with regular stops or an overnight stay.
- If you feel yourself falling asleep while driving, stop in a safe place and take a break.

'I wrote a diary and marked down what I could do and how long it would take me. I wrote down positive achievements and new things I had accomplished. I began to see that I was improving month on month and sometimes even week on week. I may be a long way off where I was before cancer, but I am a long way towards a new normal.'

**Elizabeth**

# Coping with fatigue at work

You may find fatigue affects your ability to work in the way that you used to. Talking to your employer about reasonable adjustments could help you return to work at a pace that suits you.

Reasonable adjustments are things you can do for yourself to manage tiredness at work, but also ways that your employer can help.

You could talk to your employer about:

- changing your hours, or working less
- changing your start and finish time so you can travel to and from work at less busy times
- sharing some of your work with other colleagues
- having a comfortable room that you can go to for regular short breaks
- having a parking place near to where you work
- allowing you to work from home sometimes, or regularly
- doing lighter work if your job involves physical exertion or heavy lifting.

Explaining the effects of fatigue to your colleagues might also help you manage your fatigue at work. It can help them to understand what you are coping with. It may be difficult for some people to know how tired you are, especially if you look well.

Doing regular physical activity when you are at work can help too. Even taking a short walk on your lunch break could give you more energy. It can also help to reduce stress.

If you are self-employed, it can help to talk to the Department for Work and Pensions (see pages 72 to 73 for contact details) about benefits that you may be entitled to claim.

We have more information about work and cancer and self-employment and cancer on our website.

You may also find our booklets **Work and cancer**, **Self-employment and cancer**, and our leaflet **Questions to ask about work and cancer**, helpful.

**Work and cancer** is also available as an audiobook if you find it easier to listen when you are tired. See page 64 for ways to order these resources.

'I had a list of things, like more flexible hours, being able to go and take breaks and having a quiet room where I could go and lie down.'

**Ruth**



# LOOKING AFTER SOMEONE WITH FATIGUE

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Caring for someone with fatigue

52

# Caring for someone with fatigue

Many people give support to a family member, partner, friend, or neighbour who has fatigue. Caring for (looking after) someone with fatigue can mean many things, such as helping with personal care, providing transport or organising appointments.

If you are caring for someone with fatigue, there are many simple things that you can do to help:

- Acknowledge that fatigue is difficult for you both.
- Use a fatigue diary to plan. This will help you both see when the person with fatigue has more or less energy to do things. A diary is attached to the inside of the back cover of this booklet.
- Try to help the person you care for reduce their fatigue by helping them be more active or make changes to their diet.

You can also go to appointments at the hospital with the person you care for. You could help them explain to the healthcare team how the fatigue is affecting you both. You could show them the person's fatigue diary and ask their advice about what else you can do to help.

## Looking after yourself

When you are caring for someone else it is important to look after yourself too. Make sure you keep up with your own health appointments. This includes any vaccinations you need, such as the flu jab. If you are taking any medicines regularly, it is important you have a supply of these.

If you can, try to:

- take breaks
- eat well
- be active
- get a good night's sleep
- get some support for yourself – perhaps by chatting to other carers in a support group or on our Online Community ([maccmillan.org.uk/community](https://www.maccmillan.org.uk/community)).

We have more information for when you are looking after someone with cancer and how to get help if you need it (see page 64 for ways to order).





# WORK AND FINANCIAL SUPPORT

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Work	56
Financial help and benefits	58

# Work

You may not know how cancer will affect your work, now or in the future.

It is a good idea to talk to your manager early on. If your workplace has a human resources (HR) or personnel department, contact them as soon as you can. If they know how the cancer or treatment may affect your ability to work, they can support you better.

Some people stop working during cancer treatment and for a while after, until they feel ready to go back. Others carry on working, perhaps with reduced hours or other changes to their job.

Some people may decide not to go back to work. Or they may choose to do something different. Others may not be able to go back to work because of the effects of cancer on their health. Going back to work may depend on the type of work you do or how much your income is affected.

It is important not to take on too much, too soon. Your cancer doctor, GP or specialist nurse can help you decide when and if you should go back to work.

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful – see page 64. There is also lots more information at [macmillan.org.uk/work](https://www.macmillan.org.uk/work)

## Employment rights

If you have, or have ever had cancer, the law considers you to be disabled. This means you cannot be treated differently (less favourably) than other people at work because of cancer. If you are treated less favourably because of cancer, this is called discrimination.

The law also says your employer has to make reasonable adjustments (changes) to your workplace and their work practices.

If you live in England, Scotland or Wales, you are protected by the Equality Act 2010. If you live in Northern Ireland, you are protected by the Disability Discrimination Act 1995.

Our booklet **Your rights at work when you are affected by cancer** has more information – see page 64.

'My manager knows about the cancer and the fatigue. They have been really good. I am seen as an asset rather than a problem, which helps a lot.'

**Ruth**

# Financial help and benefits

When you are affected by cancer, you might need help with extra costs. Or you might need financial support if you have to stop working.

## Statutory Sick Pay

If you work for an employer and take time off sick, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks.

## Benefits

Benefits are payments from the government to people who need financial help. You can find out more about benefits and apply for them online. Go to **gov.uk** if you live in England, Wales and Scotland or **nidirect.gov.uk** if you live in Northern Ireland.

Here are some benefits that you might be able to get if you are affected by cancer.

## Employment and Support Allowance (ESA)

This benefit is for people under state pension age who cannot work because of illness or disability. There are different types of ESA:

- Contribution-based ESA may be available if you have paid enough National Insurance.
- Income-related ESA may be available if your income and savings are low, or if you cannot get contribution-based ESA. Income-related ESA is gradually being replaced by a new benefit called Universal Credit.

## Personal Independence Payment

This benefit is for people aged between 16 and 64 who have problems moving around and looking after themselves. You must have had these difficulties for at least 3 months and expect them to last for at least 9 months.

## Attendance Allowance

This benefit is for people aged 65 or over who have problems looking after themselves because of an illness or disability. This could mean getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months.

## Special rules

If you are terminally ill, and your doctor thinks you may be expected to live for less than 6 months, you can apply for some benefits using a fast-track process called special rules. Your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate. It does not matter if you live longer than 6 months. Your doctor or specialist nurse will need to fill out a form for you.

## Help for carers

Carer's Allowance is a weekly benefit that helps people who look after someone with a lot of care needs. If you do not qualify for it, you can apply for Carer's Credit.

Carer's Credit helps prevent gaps in your National Insurance record if you have to stop working while you are caring for someone else. You do not get money, but it protects your right to a State Pension later in life.

## Macmillan Grants

Macmillan Grants are small, mostly one-off payments to help people with the extra costs that cancer can cause. They are for people who have a low level of income and savings.

If you need things like extra clothing, help paying heating bills or even a relaxing holiday, you may be able to get a Macmillan Grant.

How much you get will depend on your situation and needs. The average grant is around £400. A grant from Macmillan would not normally affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

## Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. This includes life and travel insurance. A cancer diagnosis might also mean that you can get a payout from an insurance scheme that you already have.

If you are looking into buying insurance or making a claim, one of our financial advisers can help. Call **0808 808 00 00**.

We have more information in our booklets **Insurance** and **Travel and cancer** – see page 64. Our Online Community forum **Travel insurance** may also be helpful. Visit **[macmillan.org.uk/travelinsurancegroup](https://www.macmillan.org.uk/travelinsurancegroup)**

## More information

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced welfare rights advisers and financial guides. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00**.

You can also get information about benefits and other types of financial help from Citizens Advice – see page 72.

Our booklet **Help with the cost of cancer** has lots more information – see page 64.





# FURTHER INFORMATION

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About our information	64
Other ways we can help you	66
Other useful organisations	69
Your notes and questions	76

# About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

## Order what you need

You may want to order more leaflets or booklets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

We have booklets on different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer and information for carers, family and friends.

## Online information

All of our information is also available at **macmillan.org.uk/information-and-support**

There you'll also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

## Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- eBooks
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats**

If you'd like us to produce information in a different format for you, email us at **cancerinformationteam@macmillan.org.uk** or call us on **0808 808 00 00**.

## Help us improve our information

We know that the people who use our information are the real experts. That's why we always involve them in our work. If you've been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets.

If you'd like to hear more about becoming a reviewer, email [reviewing@macmillan.org.uk](mailto:reviewing@macmillan.org.uk) You can get involved from home whenever you like, and we don't ask for any special skills – just an interest in our cancer information.



# Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're here to support you.

## Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

### Macmillan Support Line

Our free, confidential phone line is open Monday to Friday, 9am to 8pm. Our cancer support specialists can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Call us on **0808 808 00 00** or email us via our website, **[macmillan.org.uk/talktous](https://macmillan.org.uk/talktous)**

## Information centres

Our information and support centres are based in hospitals, libraries and mobile centres.

There, you can speak with someone face to face.

Visit one to get the information you need, or if you'd like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at **[macmillan.org.uk/informationcentres](https://macmillan.org.uk/informationcentres)** or call us on **0808 808 00 00**.

## Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That's why we help to bring people together in their communities and online.

## Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting [macmillan.org.uk/selfhelpandsupport](https://www.macmillan.org.uk/selfhelpandsupport)

## Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at [macmillan.org.uk/community](https://www.macmillan.org.uk/community)

## The Macmillan healthcare team

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

'Everyone is so supportive on the Online Community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'

Mal

### **Help with money worries**

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you've been affected in this way, we can help.

### **Financial guidance**

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

### **Help accessing benefits**

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

### **Macmillan Grants**

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

### **Help with work and cancer**

Whether you're an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit **macmillan.org.uk/work**

### **My Organiser app**

Our free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search 'My Organiser' on the Apple App Store or Google Play on your phone.

# Other useful organisations

There are lots of other organisations that can give you information or support.

## Complementary health organisations

### British Acupuncture Council

**Tel** 0208 735 0400

**Email** [info@acupuncture.org.uk](mailto:info@acupuncture.org.uk)

**[www.acupuncture.org.uk](http://www.acupuncture.org.uk)**

Regulatory body for the practice of traditional acupuncture.

You can download a list of practitioners from the website.

### The British Complementary Medicine Association (BCMA)

**Tel** 0845 345 5977

(Mon, Tue, Thu and Fri, 10am to 5pm)

**Email** [office@bcma.co.uk](mailto:office@bcma.co.uk)

**[www.bcma.co.uk](http://www.bcma.co.uk)**

Lists therapists and organisations that are members of the BCMA and meet its code of ethics.

### British Holistic Medical Association **[www.bhma.org](http://www.bhma.org)**

Organisation of health professionals, practitioners, and members of the public who want to adopt a more holistic approach to their lives. Produces self-help books and CDs.

### British Reflexology Association

**Tel** 0188 682 1207

**Email** [bra@britreflex.co.uk](mailto:bra@britreflex.co.uk)

**[www.britreflex.co.uk](http://www.britreflex.co.uk)**

Their website provides a list of practitioners and you can buy books and DVDs about reflexology.

## General cancer support organisations

### Cancer Black Care

**Tel** 0208 961 4151

#### Email

[info@cancerblackcare.org.uk](mailto:info@cancerblackcare.org.uk)

**[www.cancerblackcare.org.uk](http://www.cancerblackcare.org.uk)**

Offers UK-wide information and support for people with cancer, as well as their friends, carers and families, with a focus on those from BME communities.

### Cancer Focus

#### Northern Ireland

**Helpline** 0800 783 3339

(Mon to Fri, 9am to 1pm)

#### Email

[nurseline@cancerfocusni.org](mailto:nurseline@cancerfocusni.org)

**[www.cancerfocusni.org](http://www.cancerfocusni.org)**

Offers a variety of services to people affected by cancer in Northern Ireland, including a free helpline, counselling and links to local support groups.

### Cancer Research UK

**Helpline** 0808 800 4040

(Mon to Fri, 9am to 5pm)

**[www.cancerresearchuk.org](http://www.cancerresearchuk.org)**

A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

### Cancer Support Scotland

**Tel** 0800 652 4531

(Mon to Fri, 9am to 5pm)

#### Email

[info@cancersupportscotland.org](mailto:info@cancersupportscotland.org)

**[www.cancersupportscotland.org](http://www.cancersupportscotland.org)**

Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

### Maggie's Centres

**Tel** 0300 123 1801

#### Email

[enquiries@maggiescentres.org](mailto:enquiries@maggiescentres.org)

**[www.maggiescentres.org](http://www.maggiescentres.org)**

Has a network of centres in various locations throughout the UK. Provides free information about cancer and financial benefits.

Also offers emotional and social support to people with cancer, their family, and friends.

## **Penny Brohn UK**

**Helpline** 0303 300 0118

(Mon to Fri, 9.30am to 5pm)

### **Email**

helpline@pennybrohn.org.uk

**www.pennybrohn.org.uk**

Offers a combination of physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

## **Tenovus**

**Helpline** 0808 808 1010

(Daily, 8am to 8pm)

### **Email**

info@tenovuscancercare.org.uk

**www.tenovuscancercare.org.uk**

Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

## **Counselling**

### **British Association for Counselling and Psychotherapy (BACP)**

**Tel** 0145 588 3300

**Email** bacp@bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor at **itsgoodtotalk.org.uk**

### **UK Council for Psychotherapy (UKCP)**

**Tel** 0207 014 9955

**Email** info@ukcp.org.uk

**www.psychotherapy.org.uk**

Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

## Emotional and mental health support

### Mind

**Helpline** 0300 123 3393

**Text** 86463

**Email** [info@mind.org.uk](mailto:info@mind.org.uk)

**www.mind.org.uk**

Provides information, advice and support to anyone with a mental health problem through its helpline and website.

## Financial or legal advice and information

### Benefit Enquiry Line

#### Northern Ireland

**Helpline** 0800 022 2450

(Mon, Tue, Wed and Fri, 9am to 5pm, and Thu, 10am to 5pm)

**Textphone** 0289 031 1092

**www.nidirect.gov.uk/  
money-tax-and-benefits**

Provides information and advice about disability benefits and carers' benefits in Northern Ireland. You can also call the Make the Call helpline on 0800 232 1271 to check you are getting all the benefits you are eligible for

### Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use their online webchat or find details for your local office in the phone book or by contacting:

#### England

**Helpline** 03444 111 444

**www.citizensadvice.org.uk**

#### Wales

**Helpline** 03444 77 2020

**www.citizensadvice.org.uk/  
wales**

#### Scotland

**Helpline** 0808 800 9060

**www.citizensadvice.org.uk/  
scotland**

#### Northern Ireland

**Helpline** 0800 028 1181

**www.citizensadvice.co.uk**

**Department for Work  
and Pensions (DWP)  
Personal Independence  
Payment (PIP) Helpline**

0345 121 4433

(Mon to Fri, 8am to 6pm)

**Textphone** 000 121 4493

**Carer's Allowance Unit**

**Tel** 0800 731 0297

(Mon to Fri, 8am to 6pm)

**Textphone** 0800 731 0317

**[www.gov.uk/browse/  
benefits](http://www.gov.uk/browse/benefits)**

Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

**GOV.UK**

**[www.gov.uk](http://www.gov.uk)**

Has information about social security benefits and public services in England, Scotland and Wales.

**Unbiased.co.uk**

**Helpline** 0800 023 6868

**Email** [contact@unbiased.co.uk](mailto:contact@unbiased.co.uk)

**[www.unbiased.co.uk](http://www.unbiased.co.uk)**

You can search the website for qualified advisers in the UK who can give expert advice about finances, mortgages, accounting or legal issues.

**Equipment and advice  
on living with a disability**

**Disability Rights UK**

**Tel** 0207 250 8181

(Mon to Fri, 10am to 12.30pm,  
then 1.30pm to 4pm)

**Email**

[enquiries@disabilityrightsuk.org](mailto:enquiries@disabilityrightsuk.org)

**[www.disabilityrightsuk.org](http://www.disabilityrightsuk.org)**

Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for disabled students.

**Scope**

**Helpline** 0808 800 3333

(Mon to Fri, 9am to 5pm)

**Email** [helpline@scope.org.uk](mailto:helpline@scope.org.uk)

**[www.scope.org.uk](http://www.scope.org.uk)**

Offers confidential advice and information on living with disability. Also supports an independent, UK-wide network of local Disability Information and Advice Line services (DIALs) run by and for disabled people.

## Support for young people

### **CLIC Sargent**

**Tel** 0300 330 0803

**www.clicsargent.org.uk**

Provides clinical, practical, financial and emotional support to children with cancer in the UK.

### **Teenage Cancer Trust**

**Tel** 0207 612 0370

(Mon to Fri, 9am to 5.30pm)

#### **Email**

hello@teenagecancertrust.org

**www.teenagecancertrust.org**

A UK-wide charity devoted to improving the lives of teenagers and young adults with cancer.

Runs a support network for young people with cancer, their friends and families.

### **Youth Access**

**Tel** 020 8772 9900

(Mon to Fri, 9.30am to 1pm, then 2pm to 5.30pm)

#### **Email**

admin@youthaccess.org.uk

**www.youthaccess.org.uk**

A UK-wide organisation providing counselling and information for young people. Find your local service by visiting **youthaccess.org.uk/find-your-local-service**

## Support for older people

### **Age UK**

**Helpline** 0800 678 1174

(Daily, 8am to 7pm)

**www.ageuk.org.uk**

Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

## LGBT-specific support

### **LGBT Foundation**

**Tel** 0345 330 3030

(Mon to Fri, 10am to 10pm, and Sat 10am to 6pm)

**Email** helpline@lgbt.foundation

**www.lgbt.foundation**

Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

## Support for carers

### **Carers Trust**

**Tel** 0300 772 9600

(Mon to Fri, 9am to 5pm)

**Email** [info@carers.org](mailto:info@carers.org)

**[www.carers.org](http://www.carers.org)**

Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

### **Carers UK**

#### **Helpline**

**(England, Scotland, Wales)**

0808 808 7777

(Mon to Wed, 10am to 4pm)

**Helpline (Northern Ireland)**

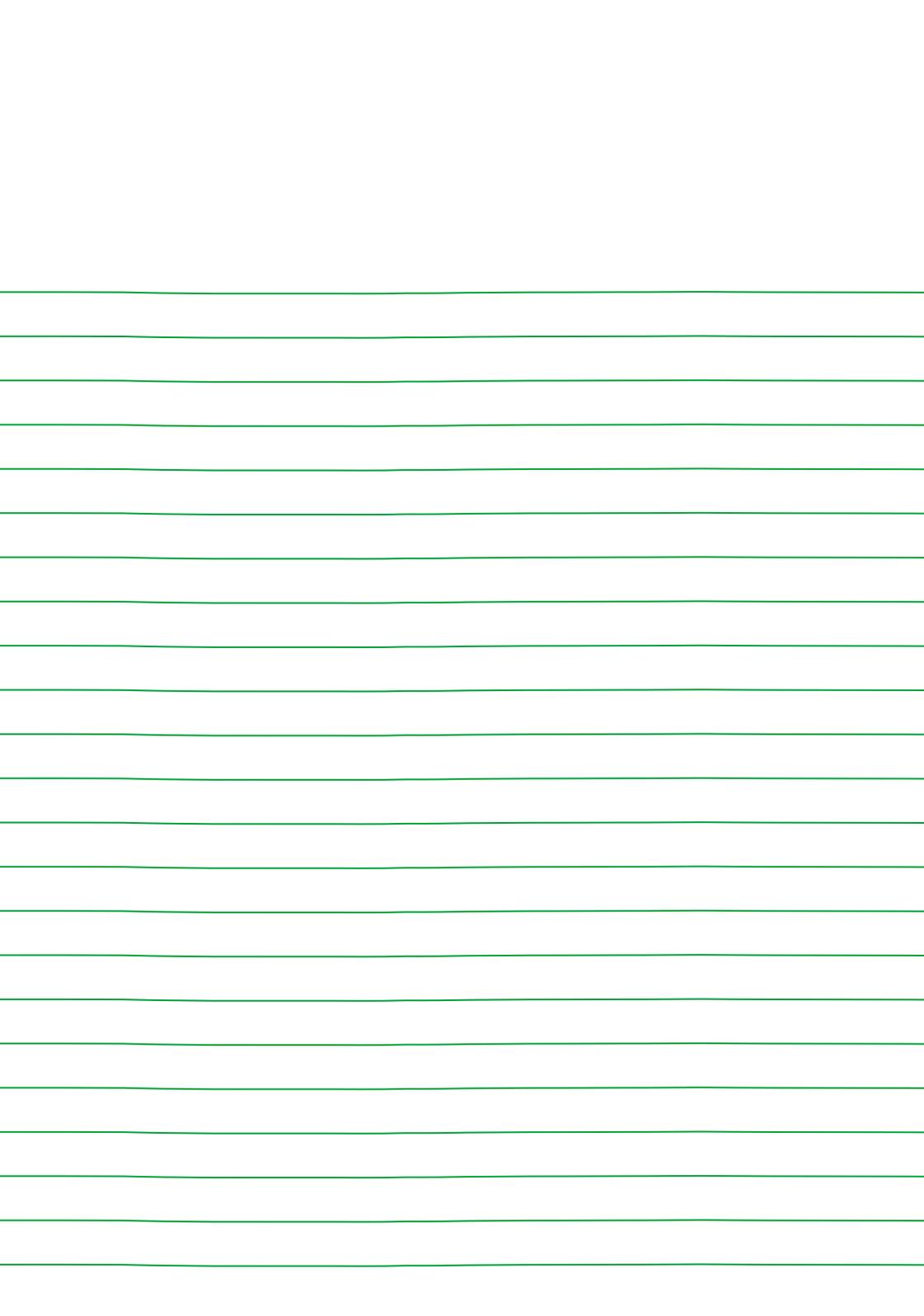
028 9043 9843

**Email** [advice@carersuk.org](mailto:advice@carersuk.org)

**[www.carersuk.org](http://www.carersuk.org)**

Offers information and support to carers across the UK. Has an online forum and can put people in contact with support groups for carers in their area.





## Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos may be of models.

## Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Chief Medical Editor, Dr Tim Iveson, Macmillan Consultant Medical Oncologist.

With thanks to: Charlotte Argyle, Macmillan Carers Support Programme Manager; Suzanne Bridger Macmillan Palliative Care CNS; Dr Jackie Gracey, Lecturer in Physiotherapy; and Dr Ollie Minton, Macmillan Consultant in Palliative Medicine. Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

We welcome feedback on our information. If you have any, please contact [\*\*cancerinformationteam@macmillan.org.uk\*\*](mailto:cancerinformationteam@macmillan.org.uk)

## Sources

We have listed a sample of the sources used in the booklet below. If you would like further information about the sources we use, please contact us at [\*\*cancerinformationteam@macmillan.org.uk\*\*](mailto:cancerinformationteam@macmillan.org.uk)

Macmillan Cancer Support. Cured but at what cost? Long term consequences of cancer treatment. 2013.

NCCN. Clinical practice guidelines in cancer related fatigue. 2018.

NHS Scotland. Scottish palliative care guidelines – weakness and fatigue. 2014.

# Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we're there to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.



## **Share your cancer experience**

Support people living with cancer by telling your story, online, in the media or face to face.

## **Campaign for change**

We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

## **Help someone in your community**

A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

## **Raise money**

Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

## **Give money**

Big or small, every penny helps. To make a one-off donation see over.

## **Call us to find out more**

**0300 1000 200**

[macmillan.org.uk/getinvolved](http://macmillan.org.uk/getinvolved)

## Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £

(Please delete as appropriate)

I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support

OR debit my:

Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

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Valid from

□□	□□
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Expiry date

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Issue no

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Security number

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Signature

Date

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## Don't let the taxman keep your money

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If you'd rather donate online go to [macmillan.org.uk/donate](https://macmillan.org.uk/donate)

Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851, 89 Albert Embankment, London SE1 7UQ

This booklet is about coping with fatigue caused by cancer or its treatment (cancer-related fatigue). Fatigue means feeling very tired or exhausted all or most of the time. The tiredness is not helped by rest and can affect you physically and emotionally.

This booklet is for anyone who has cancer-related fatigue. There is also information for carers, family members and friends.

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, Monday to Friday, 9am to 8pm, or visit **macmillan.org.uk**

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

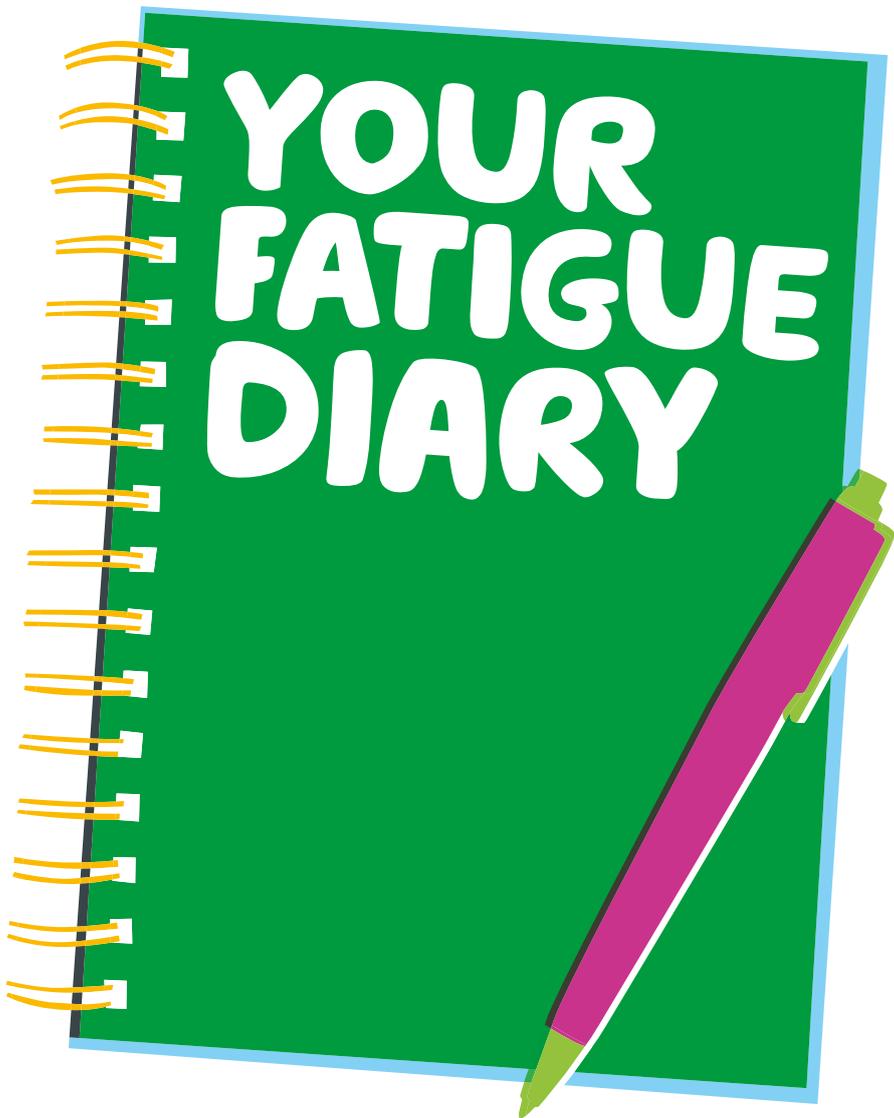
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What's this logo? Visit **macmillan.org.uk/ourinformation**

**WE ARE  
MACMILLAN.  
CANCER SUPPORT**



Keep track of  
your daily energy  
levels here

**MACMILLAN**  
CANCER SUPPORT

# Your fatigue diary

Keeping a daily diary of your energy levels and when you have treatment can help you work out how treatment affects you. This diary has enough space to record your energy levels for 1 month.

You may want to photocopy this diary before you use it, in case you want more pages later. Or download and print free copies from **[macmillan.org.uk/fatigue](http://macmillan.org.uk/fatigue)**

You can use this fatigue diary to:

- see what times of day you have the most energy
- note down things that might be affecting your fatigue or any progress you have made
- plan your important activities for when you have the most energy
- look at your last week and decide if you planned too much or not enough for your next week
- work out what makes your fatigue better or worse.

# How to use your diary

Using this scale of 1 to 5, record your energy levels in the diary:

- 1 No fatigue** – able to do all normal activities.
- 2 Mild fatigue** – able to do most normal activities.
- 3 Moderate fatigue** – able to do some activities but need rest.
- 4 Severe fatigue** – difficulty walking or doing activities such as cooking or shopping.
- 5 Extreme fatigue** – needing to sleep or rest all day.

You may want to put a cross or record days you have treatment or do a certain activity. This can help you see how and when treatment affects your energy levels.

We have included some examples of what you might write in your diary. You can see these in the first line of the table.

You can share this information with your cancer doctor or nurse. They will be able to offer you more effective treatment for fatigue, based on your notes.

Day	Morning	Afternoon	Evening	Treatment or activity	Other notes
Monday	1	2	3	Had chemotherapy at 2pm. Or, went for a short walk.	Felt very tired and had a nap. Or, slept better after exercise.
Tuesday					
Wednesday					
Thursday					
Friday					
Saturday					
Sunday					

<b>Day</b>	<b>Morning</b>	<b>Afternoon</b>	<b>Evening</b>	<b>Treatment or activity</b>	<b>Other notes</b>
Monday					
Tuesday					
Wednesday					
Thursday					
Friday					
Saturday					
Sunday					

<b>Day</b>	<b>Morning</b>	<b>Afternoon</b>	<b>Evening</b>	<b>Treatment or activity</b>	<b>Other notes</b>
Monday					
Tuesday					
Wednesday					
Thursday					
Friday					
Saturday					
Sunday					

<b>Day</b>	<b>Morning</b>	<b>Afternoon</b>	<b>Evening</b>	<b>Treatment or activity</b>	<b>Other notes</b>
Monday					
Tuesday					
Wednesday					
Thursday					
Friday					
Saturday					
Sunday					

My consultant is:

---

My specialist nurse is:

---

Contact numbers: \_\_\_\_\_

---

Out-of-hours contact number: \_\_\_\_\_

Will you tell us what you think of this diary?

Visit [surveymonkey.co.uk/r/fatiguediary](https://www.surveymonkey.co.uk/r/fatiguediary)

or scan this QR code:



We're here to help you find your best way through from the moment of diagnosis, so you're able to live life as fully as you can. For information, support or just someone to talk to, call **0808 808 00 00** or **macmillan.org.uk**

This diary is part of Macmillan's booklet **Coping with fatigue (tiredness)**.  
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