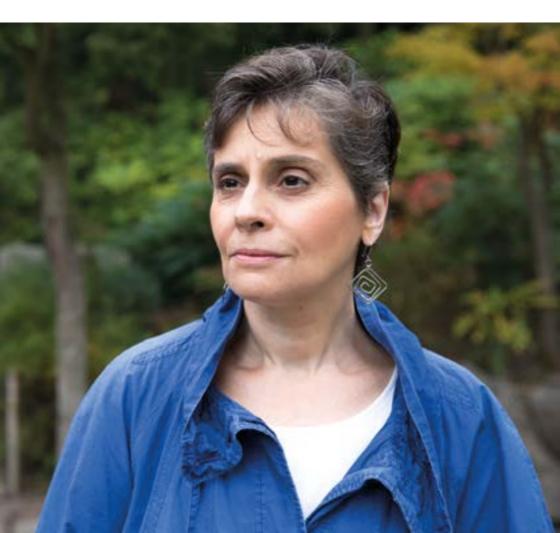


Coping with fatigue (tiredness)





I found that if someone said the word 'tired', I got irritated. I thought, this is not tiredness, it's not even exhaustion – it's not being able to do anything that you normally would.

Androulla, diagnosed with breast 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. This feeling is not helped by rest. The booklet is for anyone who has cancer-related fatigue. There is also information for carers, family members and friends.

This booklet explains the causes and effects 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

This 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 <u>contents list</u> to help you.

This booklet contains a lot of information. You may find it difficult to read this booklet all at once if you are feeling tired. It is fine to skip parts of the booklet and come back to them when you are ready.

If reading makes you tired, you may wish to listen to this booklet as an audiobook. Visit <u>be.macmillan.org.uk</u> or call us on <u>0808 808 00 00</u>.

You can download our <u>fatigue diary</u> which has enough space to record your energy levels for 1 month. We have more information about <u>using a</u> <u>fatigue diary</u>.

At the <u>end of the booklet</u> there are details of other organisations that can help.

Quotes

In this booklet, we have included quotes from people who have cancer-related fatigue, which you may find helpful. These are from people who have chosen to share their story with us. This includes Androulla, who is on the cover of this booklet. To share your experience, visit <u>macmillan.org.uk/shareyourstory</u>

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on <u>0808 808 00 00</u>, 7 days a week, 8am to 8pm, or visit <u>macmillan.org.uk</u>

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using NGT (Text Relay) on <u>18001 0808 808 00 00</u>, or use the NGT Lite app.

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, interactive PDFs, large print and translations. To order these, visit <u>macmillan.org.uk/otherformats</u> or call <u>0808 808 00 00</u>.

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Fatigue and its effects

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What is fatigue (tiredness)?

Fatigue is feeling very tired or exhausted most, or all, of the time. Cancer and cancer treatments can cause fatigue. Fatigue in people with cancer is sometimes called cancer-related fatigue or CRF. CRF is a very common problem. Most people who have cancer will experience fatigue at some point.

Fatigue is different from the tiredness that someone without cancer may have. The tiredness can be more severe. And people with cancer may get tired more quickly after less activity. They may feel physically, emotionally, and mentally exhausted even if they are getting enough rest and sleep.

The fatigue differs one day to the next, but even a trip to buy some groceries leaves me completely shattered.

Mason, diagnosed with anaplastic astrocytoma

Fatigue affects everyone differently. It can vary throughout the day, and each day may be different.

There is no way to know how long fatigue may last for each person. For most people, fatigue gets better after treatment finishes. But for some it may continue for months or sometimes years.

It is important to talk with your doctor or nurse about how you are feeling. Tell them about any signs of fatigue, as there may be things they can do to help. For example, they may be able to treat some of the causes of fatigue such as anaemia (low number of red blood cells).

We have more information about treating the <u>causes of fatigue</u>.

There are also things you can do for yourself that may help. For example, you could try planning your days so that you have the energy to do the things you want to do most. We have more information on <u>ways to manage fatigue</u>.

The effects of fatigue

For some people, cancer-related fatigue can affect all aspects of daily life. For others, the fatigue is very mild and does not affect them as much.

Some of the more common effects of fatigue include:

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

Having 1 or more of these symptoms 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 affect you financially. You might find it helpful to read our booklets <u>Work and cancer</u> or <u>Work and cancer – easy read</u>, and <u>Your rights at</u> <u>work when you are affected by cancer</u>.

You can order, download or listen to our information in printed and audio format for free, from our website. Visit <u>be.macmillan.org.uk</u> or call us on <u>0808 808 00 00</u>.

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

Fatigue may also affect you if you have other health conditions. For example, people who have diabetes may already be tired because of the diabetes. Cancer-related fatigue may make this worse.

There are things you can do to help <u>manage fatigue</u>. But it is important to tell your healthcare team how you are feeling and how fatigue is affecting your life. Getting support from your healthcare team may help prevent or relieve some of these effects. It may also help improve your quality of life.

I remember there was a booklet from Macmillan that I had on the side of the table and I was so fatigued I couldn't even lift it – the fatigue was that bad.

Androulla, diagnosed with breast cancer



Causes of fatigue

What causes fatigue?

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What causes fatigue?

We do not fully understand what causes cancer-related fatigue (CRF). There may be many reasons for it, including:

- the cancer itself
- cancer treatments
- anaemia (low number of red blood cells)
- loss of appetite
- pain
- other health conditions, such as diabetes
- trouble sleeping
- your feelings, such as anxiety.

The cancer itself

Sometimes, the cancer itself may cause fatigue. Cancers such as myelofibrosis (MF) are known to cause tiredness.

Other cancers such as breast and prostate cancer can change the levels of hormones in your body. This change can affect the way the body uses energy, and may cause fatigue.

Cancer may affect the levels of cytokines in the body. Cytokines are a type of protein. They help control some of the things that cells do. Research has suggested that cytokines may be involved in cancer-related fatigue. Some cancers cells can irritate the lining of the tummy and make it produce too much fluid (ascites). This can cause bloating and discomfort in the tummy. Ascites can also cause fatigue.

Blood cancers such as lymphoma can reduce the number of red blood cells. Red blood cells are made in the bone marrow. They contain haemoglobin which carries oxygen to the cells. A low number of red blood cells is called anaemia. It can cause fatigue.

Cancer treatments

Some cancer treatments can cause anaemia, which can cause fatigue. But doctors are still learning about why cancer treatments can cause fatigue. It might be 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. You may have been anxious before your operation and not been sleeping well. This can cause you to feel tired. Some painkillers can also make you feel tired.

Tiredness after surgery will usually improve after a few weeks. However, some types of surgery may cause continuing problems with fatigue. For example, if you have had surgery to the stomach, you may have problems 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 as cycles of treatment that are a few weeks apart. Some people feel very tired in the first few days after chemotherapy. But they may find they feel better before the next cycle. However, fatigue often builds up and 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 can be different for everyone. It usually improves after you finish your treatment. But sometimes it can become a long-term problem. These treatments can cause other long-term effects such as breathlessness or heart problems. These effects are likely to make you feel more tired.

Many people find their energy levels return to normal within 6 to 12 months after their treatment finishes. However, some people still feel tired and have low energy levels a year or so later. Sometimes tiredness can continue for 2 years or more, but this is not common.

You can find more information in our booklets <u>Understanding</u> <u>chemotherapy</u> and <u>Understanding radiotherapy</u>.

Hormonal therapy

Hormones are substances produced naturally in the body. They act as chemical messengers and influence the activity of cells. Some cancers depend on hormones to grow.

Hormonal therapies work by changing the production or activity of hormones in the body. They are most commonly used to treat breast and prostate cancer. There are several different types of hormonal therapy. Some hormonal therapies can cause fatigue. You can find out more about hormonal therapy on our website at <u>macmillan.org.uk/</u><u>hormonal-therapy</u>

Targeted therapy

Targeted therapy uses drugs to find and attack cancer cells. There are many different types of targeted therapy. Each type targets something in or around the cancer cell that is helping it to grow and survive.

Types of targeted therapy include:

- cancer growth inhibitors
- angiogenesis inhibitors
- monoclonal antibodies.

Some types of targeted therapy can cause fatigue. You can find out more about hormonal therapy on our website at <u>macmillan.org.uk/</u><u>targeted-therapy</u>

Immunotherapy

The immune system protects the body against illness and infection. Immunotherapies are treatments that use the immune system to find and attack cancer cells. There are different types of immunotherapy. These include:

- checkpoint inhibitors
- monoclonal antibodies
- immune system modulators.

Some types of immunotherapy can cause fatigue. You can find out more about hormonal therapy on our website at <u>macmillan.org.uk/</u><u>immunotherapy</u>

Anaemia

Anaemia is when you have a low number of red blood cells. Many people with cancer have anaemia at some point. This is called being anaemic.

Red blood cells contain a protein called haemoglobin (Hb), which carries oxygen around the body. If you do not have enough red blood cells, your body does not have enough haemoglobin. This reduces the amount of oxygen your body gets, which can make you feel very tired.

You may also:

- feel breathless
- feel dizzy and light-headed
- have chest tightness.

It is important to tell your doctor or nurse if you have any of these symptoms.

If you have symptoms of anaemia or are having cancer treatment, you will have a blood test called a full blood count (FBC). This checks the level of haemoglobin in your blood.

Causes of anaemia

Anaemia can be caused by different things. These include:

- the cancer itself some cancers cause fewer red blood cells to be made in the bone marrow, or they may cause bleeding
- chemotherapy chemotherapy can reduce the number of red blood cells you make
- radiotherapy radiotherapy can cause anaemia if it is given to a part of the body containing bone marrow, including the hip bone or breastbone (sternum)
- eating problems a shortage of vitamins and minerals, especially iron and vitamin B12, means your body may not make enough red blood cells.

Treatments for anaemia

If you are anaemic, your doctor may be able to give you treatment that can help. The main treatment is a blood transfusion. This is when you have a drip (transfusion) of red blood cells given directly into your bloodstream. This can quickly increase the number of red blood cells in the body. Some people feel better very soon after having a blood transfusion.

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

If your iron levels are low, you may be offered an iron infusion (drip). This is a way to increase the body's iron levels quickly. Your doctor or nurse can explain more about having an iron infusion.

Eating problems

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

- you cannot eat the same amount of food as usual
- 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.

Some people lose weight even if they are eating a lot, because of the effect of the cancer on the body.

If you feel sick (nausea), you may not want to eat. And if you are sick (vomit), your body will not be able to absorb nutrients from food. This can make you feel weak and tired, and you may also become dehydrated.

Your doctor can prescribe anti-sickness (anti-emetic) drugs, which usually help. Some anti-sickness drugs 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 cannot keep them down due to vomiting, speak to your doctor or nurse. They may suggest other ways of taking anti-sickness medicines.

Chemotherapy can affect your 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 your family or friends if they could prepare food for you. Or you could buy some ready-made meals. Some organisations deliver ready 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.

If you have a poor appetite, 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 a pharmacy. Some are available on prescription. Unflavoured high-energy powders can add calories to food without making the portion 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. Read our booklet <u>Eating problems and cancer</u> or visit our website at <u>macmillan.org.uk/eating-problems</u>



Pain

Having cancer does not mean you will have pain. But if you do have pain there are different medicines and treatments that can help. When pain is not treated, it is common to feel anxious, irritable, frustrated and depressed. We have more information about <u>your feelings</u>. We also have more information on our website at <u>macmillan.org.uk/depression</u>

Pain can also cause fatigue. The best way to deal with fatigue caused by pain is to manage the pain.

It is important to tell your GP, cancer doctor or specialist nurse if you are in pain. Talk to them about how it is affecting you. Relieving pain is an important part of your treatment and care.

Some strong painkillers such as morphine may make you feel sleepy or drowsy.

We have more information about managing pain in our <u>booklet</u> and <u>audiobook</u> Managing cancer pain.

Some people find non-drug treatments and complementary therapies such as acupuncture and relaxation help their pain. You can find out more about these treatments on our website <u>macmillan.org.uk/</u> <u>pain-management-without-drugs</u>

Other health conditions

Other health conditions, such as 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.

Trouble sleeping

How we sleep and how much sleep we need can be different for everyone. Sleep is important for:

- physical health
- emotional well-being
- restoring energy
- concentration and memory.

Sleep problems when you have cancer are very common. Losing a night of sleep will not have any effect other than making you feel tired the next day. But trouble sleeping (insomnia) over a long period of time can lead to fatigue, low mood and difficulties with concentration and making decisions.

We have more information about trouble sleeping (insomnia) on our website at <u>macmillan.org.uk/trouble-sleeping</u>

There are also things you can do for a better night's sleep.

"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 went for a walk around the ward. It turned out that I was doing about 2 miles a day. "

Mike, diagnosed with lymphoma

Your feelings

Fatigue can be made worse by:

- anxiety
- depression
- stress and tension
- poor sleeping patterns.

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 talk about how you feel with a partner, family member or close friend. Some people find it helpful to talk to people at a local support group or join an online support group.

Macmillan's Online Community is a place where you can talk to others who understand what you are going through. Visit <u>macmillan.org.uk/</u> <u>community</u>

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



Diagnosing fatigue

Diagnosing cancer-related fatigue

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Diagnosing cancer-related fatigue

It can be difficult to test or measure fatigue. If you think you might be experiencing cancer-related fatigue (CRF), talk to your cancer doctor, specialist nurse or GP. They can talk to you about ways they can help.

Assessing fatigue

How fatigue is managed depends on what is causing it.

Before your fatigue can be treated, it is important that it is properly assessed. A fatigue assessment is usually completed when you are first diagnosed, during your treatment and after you have finished treatment. But it is important to tell a member of your healthcare team if you have fatigue at any time.

Your cancer doctor, specialist nurse or GP will ask you some questions. Or they may use a questionnaire that asks you about the cancer, how you are feeling and how you cope with everyday activities.

Your specialist nurse may assess your fatigue as part of a holistic needs assessment (HNA). An HNA is a simple questionnaire that helps identify what your main concerns are.

You may be asked:

- when the fatigue started, how long it lasts and what makes it better or worse
- how the fatigue affects your daily activities
- how severe the fatigue is on a scale of 0 to 10, where 0 is no fatigue and 10 is the worst possible fatigue.

You can find out more about HNAs in our booklet <u>Holistic Needs</u> <u>Assessment: Planning your care and support</u>, and on our website at <u>macmillan.org.uk/your-hna</u>

Your cancer doctor or specialist nurse will also consider the type of cancer you have and any cancer treatments you are having or have had.

They may talk to you about:

- treatment side effects
- other symptoms such as pain or anaemia
- your emotions, for example if you are anxious or stressed
- your sleep patterns and activity levels
- your eating habits
- any other medical conditions you have such as lung, heart or hormone problems.

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 might also look at the medicines you are taking to see if adjusting them could help. For example, they may reduce the dose of a tablet that makes you sleepy.

Your healthcare team will regularly check how you are feeling, as fatigue can continue months or years after treatment. This is called a late effect of treatment. Your cancer team can tell you about the risk of developing any late effects.



I began to realise that something wasn't quite right mentally. Eventually I found out about 'chemo brain', and that many people struggle with it. This helped enormously and made a huge difference to how I felt.

Androulla



Help with fatigue

Getting help with fatigue

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Getting help with fatigue

Cancer-related fatigue (CRF) can have a big impact on your everyday life and overall sense of well-being. Talk to your healthcare team as there will be things they can do to help. They can also suggest <u>things you can do yourself</u>.

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 cancer doctor about the possible benefits and disadvantages.

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

Getting support

Usually, a team of health and social care professionals are involved in helping to manage your fatigue. Your GP or cancer doctor can help find out what's causing your fatigue and ways to manage it. For example, they can treat causes such as anaemia.

A clinical nurse specialist will assess your fatigue regularly and talk to you about practical ways to help you manage it. They can tell you if there are any support groups, or activities such as exercise classes, in your area. The support available will vary depending on where you live.

There are other health and social care professionals who can help you if you need extra support.

Physiotherapist

A physiotherapist can give you advice on exercise and moving around. They can help you plan daily activities in a way that saves you energy. They can also help you manage other symptoms, including breathlessness.

Occupational therapist

An occupational therapist (OT) provides information, support and aids to help with everyday tasks such as washing and dressing. They also help you plan activities so that you avoid doing too much and can do the things that are most important to you.

> Thanks to the support of my partner and loved ones, as well as several organisations, my life is so much better as the years have gone by.

Androulla

Social worker

A social worker can help with practical and financial problems. They can also arrange for a carer to help you at home, or respite care for any friends or family members who are looking after you. Respite care means providing cover for your usual carers so they can rest.

Counsellors

Dealing with fatigue can have an emotional impact on your well-being. <u>Counsellors</u> are trained to listen and support you with any worries or concerns.

Dealing with fatigue can be very difficult. You may find it helpful to talk to other people with fatigue. Or you can share your experience on our Online Community and get advice from others who understand what you are going through.

You can visit our Online Community at macmillan.org.uk/community

We have further information about emotional support and fatigue.

Call the Macmillan Support Line free on 0808 808 00 00, 7 days a week, 8am to 8pm.







Managing your fatigue

Things you can do

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Things you can do

There are things you can do to help manage your fatigue and increase your energy levels. We give some suggestions in this section.

Cancer-related fatigue (CRF) affects everyone differently. It may take time to find out what works for you. It is important to 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.

Using a fatigue diary

There are no medical tests to measure fatigue. Your specialist nurse may suggest using a numeric rating scale (NRS). For example, they may ask you to give your fatigue a score from 0 to 10, where 0 is no fatigue and 10 is the worst possible fatigue. Or you may be asked to rate your fatigue as none, mild, moderate or severe.

It is important that you tell your healthcare team how you feel and whether fatigue is affecting your activities. You may find it useful to keep a daily diary to:

- record your energy levels at different times of the day
- find any patterns
- find out if anything makes your fatigue better or worse
- plan important activities for when you have more energy.

To do this, you could download our <u>fatigue diary</u>. There is enough space to record your energy levels for 1 month. It explains a bit more about using a scale to describe your fatigue.

It is a good idea to share your diary with your healthcare team. They can talk to you about how you can plan your day depending on how you feel.



Physical activity

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. Staying active is the best way to keep your muscle strength and build up your energy.

There is good evidence that physical activity, such as walking quickly, is one of the best ways to help reduce the symptoms of fatigue. Being active may:

- increase your appetite
- give you more energy
- improve your sleep
- help with your mood.

If you have fatigue, being active may not always be possible. You might be nervous about starting physical activity, especially if you were not very active before your cancer treatment. But research shows that even a little activity is better than no activity at all. As you start to feel more confident, you can slowly build up the amount of physical activity you do.

Try to:

- start slowly and set some simple goals
- choose an activity or exercise that you enjoy
- get a balance between being active and getting some rest.

Before you start doing any physical activity or increase the amount you do, it is important to get advice from a healthcare professional. They can advise you on the type and amount of activity that is safe for you. 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. Or you may be referred to a community physiotherapist. 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.

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. Let your GP or cancer doctor know.

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, gentle exercise, such as walking. And simple strengthening exercises, such as climbing stairs.

Do something you enjoy, such as gardening.

We have more information about physical activity and cancer on our website at <u>macmillan.org.uk/physical-activity-cancer</u>

Our booklet <u>Physical activity and cancer</u> has more information about exercising safely when you have cancer.

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.

Eating a healthy diet may also reduce the risk of heart problems, diabetes and developing some cancers.

It can help to:

- keep a diary of what you eat and when this can help you find out 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

Many people with cancer have problems sleeping (insomnia) at some point. This can be for different reasons. For example, some medications such as steroids can affect sleep. Talk to your cancer doctor, specialist nurse or GP if you are having trouble sleeping. They may suggest things to help, such as taking your steroids earlier in the day so that you get more rest at night.

Disturbed sleep can affect energy levels and cause fatigue. 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.

Because I couldn't sleep, I felt like I was just in another world.

Androulla

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.
- Try a relaxing routine before bed. A warm bath or shower, reading or listening to soothing music might help.
- Make your bedroom a relaxing place to be. Create an area that is dark, quiet, and comfortable, but not too warm.
- 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.
- It may help to write down any worries before you go to bed so that you can try to forget about them until the next day.
- Alcohol and caffeine can stop you falling asleep. Try to cut down on alcohol and avoid caffeine close to bedtime.

We have more information on our website about difficulty sleeping macmillan.org.uk/trouble-sleeping

You may be eligible for Sleepio. This is a personalised digital programme which features a step-by-step guide to help with poor sleep (insomnia). You can find out more on the website at <u>bighealth.co.uk/lp/macmillan</u>

Complementary therapies

Some people use complementary therapies to help with fatigue, such as:

- relaxation
- mindfulness-based stress reduction (MBSR)
- yoga.

People use complementary therapies alongside conventional treatments. Complementary therapies do not claim that they can treat or cure cancer. But they may help to reduce cancer symptoms or the side effects of cancer treatments such as cancer-related fatigue. Some people find that complementary therapies make them feel more positive, and more in control of their feelings.

You can do some complementary therapies as part of a group. This can be a good way to meet other people with similar experiences, in a positive setting.

Some complementary therapies have been researched. But it is often difficult to know how effective a therapy is.

Some therapies may be available on the NHS. Your GP can give you more details. Or you may be able to get them through a <u>cancer</u> <u>support group</u> in your local area.

If you find a complementary therapist, make sure that they are qualified and registered. You can read about this at <u>macmillan.org.uk/</u> <u>complementary-therapies</u>

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

You can find out more about complementary therapies in our booklet <u>Cancer and complementary therapies</u>.

Emotional support

Dealing with fatigue can affect your feelings. If you are finding it difficult to cope, it can help to talk to someone 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 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 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 <u>services in your area</u>. You may need to pay for counselling.

Support groups

It can help to talk to other people with fatigue. You could try talking to other people at the hospital, or 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 again.

Each group is unique. There are groups for people affected by a certain type or stage of cancer, or those who are having a particular treatment. There are a small number of groups for LGBTQ+ people affected by cancer.

Ask your healthcare team about groups in your area, or call us on <u>0808 808 00 00</u>. You can also search our database for <u>groups in your area</u>.

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 ask questions, get support and give advice yourself. Our <u>Online Community</u> is a social networking site where you can talk to people, write blogs and share your experience. There are many different groups including groups for specific cancer types, family members and friends, LGBTQ+ people and practical issues.

To find support near you, visit our website at macmillan.org.uk/inyourarea



Living with fatigue

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Planning ahead

Most people do a lot when they feel good and not as much when they feel unwell. You may find that if you overdo it one day, you spend the next few days recovering. If you have fatigue, planning ahead can help. You could try planning your day so that you have energy to do the things that are most important to you.

Pacing yourself

Pacing yourself can help you manage your fatigue and be able to do what you want to do. It can help you:

- plan activities without overdoing it
- gradually increase how much you can do, including gentle exercise
- build stamina
- feel better about yourself.

Some people find that breaking down an activity into smaller stages can help. You could also think about doing an activity sitting down rather than standing up. Try to plan a rest after activities.

You could use a <u>fatigue diary</u> to keep a record. Write down the times when you feel your best and when you feel most tired. This may help you plan what time of day is best to do more tiring activities.

You can download our fatigue diary <u>here</u>.

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, 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. Cancer treatment affects people in different ways. So plan your activities for the days when you usually feel well. On days when you feel less well, it is okay to be less active and to rest more.



Managing everyday activities

If you need help with things at home, you could ask family members, friends or neighbours. Having a support network can make a big difference. Family and friends may think you are coping and might not realise you need help. Or they may be waiting for you to ask.

You may find some of the following suggestions helpful for doing everyday tasks.

Housework

- Make a list of tasks that need to be done.
- Spread tasks out over the week. Try to do a little bit each day rather than lots at one time.
- If possible, ask other people to do hard work, such as hoovering, gardening or taking the rubbish out.
- Sit down to do some tasks, if you can.
- Use long-handled dusters, mops and dustpans where possible to avoid stretching and bending.
- If possible, employ a cleaner to help. This may be expensive. Your local <u>Age UK</u> or the <u>British Red Cross</u> may be able to provide a home help service. But you may have to pay for this.

Shopping

- Make a list before you start, so you do not waste energy or time.
- If possible, go grocery shopping with a friend or family member who can help.
- Use a shopping trolley even if you are only buying a few things. You could use this to take the items back to your car if you drive.
- You could also ask shop staff to help with packing and carrying groceries to the car.
- A wheeled shopping bag may be helpful when shopping and getting things home.
- Shop at less busy times if you can.
- Most large supermarkets offer online shopping that can be delivered to your home, which you might find easier.

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 portions when you are feeling less tired and freeze them for when you feel too tired to cook.
- 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 heavy items to the table, ask for help if you can.

Washing and dressing

- If you can, sit down in the bath rather than standing in a shower as this may save your energy.
- If you have a shower, sit down if you can to avoid standing for too long. An occupational therapist (OT) may be able to provide equipment to help you in the shower.
- After a shower or bath, try wearing a towelling dressing gown and allowing yourself to dry naturally. This takes less energy than drying yourself with a towel.
- Wear clothes that are easy to put on and take off.
- Sit down when you are getting dressed.

Occupational therapists

Occupational therapists think of practical ways to make 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 any 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 them that you can do sitting down. For example, you could read, play board games or do a jigsaw puzzle.

- Try to plan activities where there are places for you to sit down while the children play.
- Avoid carrying small children if you can. Use a pram or pushchair instead.
- Try to involve children in household tasks.
- Accept help from family or friends, or ask for help. For example, someone may be able to take the 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 do have to drive, plan your trip for when you usually feel more alert. Try 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.

Coping with fatigue at work

You may find fatigue affects your ability to work in the way that you used to.

There are different ways your employer can support you at work during treatment or when you return to work.

Many employers can make changes to your workplace or working arrangements that allow you to keep working or return to work. For example, they may allow a flexible working arrangement. They may also change certain parts of your job. These are called reasonable adjustments.

If you want to keep working, talk to your manager openly about ways to make your work less tiring. This is part of making reasonable adjustments.

Possible changes could include:

- regular rests and short naps you may find this useful after an activity or a meal
- working from home if possible
- avoiding physical tasks
- planning work around times when you have more energy.

Ask your manager if there is a quiet place for you to rest at work.

<u>Using a fatigue diary</u> may help you see what days or times you are more tired. This can help you decide when it is best for you to work or rest.

You can download our <u>fatigue diary</u>.

Regular physical activity can help to reduce tiredness. Even going for a short walk on your lunch break can give you more energy. It can also help reduce stress.

Explaining how fatigue affects you can help your colleagues 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.

If you are self-employed, it can help to talk to the Department for Work and Pensions about benefits that you may be entitled to.

You might find it helpful to read our booklets:

- Work and cancer or Work and cancer easy read
- Self-employment and cancer
- Your rights at work when you are affected by cancer

There is also more information about work and cancer on our website <u>macmillan.org.uk/work</u>

It came as a shock that I couldn't manage some tasks as quickly and naturally as I had previously in the workplace.

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Looking after someone with fatigue

Caring for someone with fatigue

60

Caring for someone with fatigue

Many people support a family member, partner, friend, or neighbour who has fatigue. Caring for someone with fatigue may include helping with personal care, providing transport or organising appointments.

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

- Acknowledge that fatigue is difficult to cope with.
- 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. You can download our <u>fatigue diary</u>.
- Try to help the person you care for be more active or make changes to their diet, to <u>help them reduce their fatigue</u>.

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

Looking after yourself

You need to look after yourself when you are caring for someone else. Taking the time to focus on your own health and well-being will also benefit the person you look after.

If you look after someone, you can ask the adult social services at your local council for an assessment of your needs, to see what might help you. This is called a carer's assessment. It is important to talk about your own well-being. Adult social services can direct you to services that can help. They can also provide a one-off direct payment that you can use to do something for yourself, such as going to exercise classes or having a break.

The following tips may help:

- Talk to your GP if you are having problems eating or sleeping, are struggling with difficult feelings or are finding it hard to cope.
- Accept help from others or ask for help.
- Make sure you have time off to relax. Do something you enjoy, like reading, going for a walk or going for a meal.
- Try to eat healthy food and sit down to eat.
- Try to get out of the house every day and do some gentle exercise like walking. This can help you feel less tired and stressed.

For more information about looking after yourself when caring for someone, visit our website <u>macmillan.org.uk/yourself-carer</u>

You might also find it helpful to read our booklet for carers, <u>Looking after</u> someone with cancer.



Work and financial support

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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 or human resources (HR) department soon after you are diagnosed. This will help them to 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, sometimes with reduced hours or other changes to their job.

Your cancer doctor, GP or specialist nurse can help you decide whether you should stop working, and when and if you should go back to work.

Our booklets <u>Work and cancer</u>, <u>Working while caring for someone with</u> <u>cancer</u> and <u>Self-employment and cancer</u> have more information that may be helpful. You can also find out more about your employment rights in our booklet <u>Your rights at work when you are affected by cancer</u>.

There is also lots more information online at macmillan.org.uk/work



Help with money and benefits

When you are affected by cancer, you may need help with extra costs. Or you may need support with money if you have to stop working. We have more information online about Statutory Sick Pay and benefits you may be entitled to at <u>macmillan.org.uk/work-and-cancer</u> <u>We also have information for carers</u>.

Benefits are payments from the government to people who need help with money. You can find out more about benefits and apply for them online. Go to:

- <u>gov.uk</u> if you live in England or Wales
- <u>socialsecurity.gov.scot</u> if you live in Scotland
- <u>nidirect.gov.uk</u> if you live in Northern Ireland.

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced rights advisers and financial guides. You can speak to them by calling the Macmillan Support Line on <u>0808 808 00 00</u>. Please note the opening times may vary by service.

You can also get information about benefits and other types of financial help from <u>Citizens Advice</u> if you live in England, Scotland or Wales, or <u>Advice NI</u> if you live in Northern Ireland.

Our booklet <u>Help with the cost of cancer</u> has lots more information.

Macmillan Grants

Macmillan Grants are small, 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 or help paying heating bills, you may be able to get a Macmillan Grant. A grant from Macmillan does not affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

To find out more, or to apply, call on <u>0808 808 00 00</u> or visit <u>macmillan.org.uk/grants</u>

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance.

If you are thinking about buying insurance or making a claim, one of our financial guides can help. You can call them on <u>0808 808 00 00</u>.

We have more information in our booklet <u>Travel and cancer</u>. Our Online Community forum on Travel insurance may also be helpful at <u>macmillan.org.uk/community</u>

You can call our welfare rights advisers on <u>0808 808 00 00</u>, Monday to Friday, 8am to 8pm, and Saturday to Sunday, 9am to 5pm.





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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 booklets or leaflets like this one. Visit <u>be.macmillan.org.uk</u> or call us on <u>0808 808 00 00</u>.

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

Online information

All our information is also available online at <u>macmillan.org.uk/</u> <u>information-and-support</u> You can also find videos featuring 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

• eBooks

- Braille
- British Sign Language
- interactive PDFs
- large print
- translations.

- easy read booklets
- Find out more at macmillan.org.uk/otherformats

If you would like us to produce information in a different format for you, email us at cancerinformationteam@macmillan.org.uk or call us on <u>0808</u> 808 00 00.

The language we use

We want everyone affected by cancer to feel our information is written for them.

We want our information to be as clear as possible. To do this, we try to:

- use plain English
- explain medical words
- use short sentences
- use illustrations to explain text
- structure the information clearly
- make sure important points are clear.

We use gender-inclusive language and talk to our readers as 'you' so that everyone feels included. Where clinically necessary we use the terms 'men' and 'women' or 'male' and 'female'. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected.

You can read more about how we produce our information at <u>macmillan.org.uk/ourinfo</u>

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are 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 7 days a week, 8am to 8pm. We 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.

Our trained cancer information advisers can listen and signpost you to further support. Call us on <u>0808 808 00 00</u>. We are open 7 days a week, 8am to 8pm.

You can also email us, or use the Macmillan chat service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to <u>macmillan</u>. <u>org.uk/talktous</u> If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call <u>0808 808 00 00</u> and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

Find your nearest centre at <u>macmillan.org.uk/informationcentres</u> or call us on <u>0808 808 00 00</u>.

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help. Please note the opening times may vary by service.

Financial guidance

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

Help accessing benefits

Our welfare rights advisers can help you find out what benefits you might be entitled to, and help you complete forms and apply for benefits. They can also tell you more about other financial help that may be available to you. We can also tell you about benefits advisers in your area. Visit <u>macmillan.org.uk/financialsupport</u> to find out more about how we can help you with your finances.

Help with energy costs

Our energy advisers can help if you have difficulty paying your energy bills (gas, electricity and water). They can help you get access to schemes and charity grants to help with bills, advise you on boiler schemes and help you deal with water companies.

Macmillan Grants

Macmillan offers one-off payments to people with cancer. If you need things like extra clothing or help paying heating bills, you may be able to get a Macmillan Grant.

Call us on <u>0808 808 00 00</u> to find out more about Macmillan Grants.

Help with work and cancer

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

Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on $0808\ 808\ 00\ 00$ to speak to a work support adviser.

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 is why we help bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, family member or friend, 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 <u>macmillan.org.uk/</u> <u>selfhelpandsupport</u>

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 <u>macmillan.org.uk/community</u>

You can also use our Ask an Expert service on the Online Community. You can ask a financial guide, cancer information nurse, work support advisor or an information and support advisor any questions you have.

Macmillan healthcare professionals

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.

Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

General cancer support organisations

Cancer Black Care

Tel 0208 961 4151

Offers UK-wide information and support for people from Black and minority ethnic communities who have cancer. Also supports their friends, carers and families.

Cancer Focus Northern Ireland

Helpline 0800 783 3339

www.cancerfocusni.org Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Research UK

Helpline 0808 800 4040

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

www.cancersupportscotland.org

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

Macmillan Cancer Voices

www.macmillan.org.uk/cancervoices

A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

Maggie's

Tel 0300 123 1801

www.maggies.org

Has a network of centres in many 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**

www.pennybrohn.org.uk

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

Tenovus

Helpline 0808 808 1010

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

www.bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on the 'How to find a therapist' page.

UK Council for Psychotherapy (UKCP)

Tel 0207 014 9955

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

www.mind.org.uk

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

Samaritans

Helpline **116 123** Email **jo@samaritans.org**

www.samaritans.org

Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Financial support or legal advice and information

Advice NI

Helpline 0800 915 4604

www.adviceni.net

Provides advice on a variety of issues including financial, legal, housing and employment issues.

Benefit Enquiry Line Northern Ireland

Helpline **0800 232 1271**

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

Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Carer's Allowance Unit

Tel 0800 731 0297

Textphone **0800 731 0317**

www.gov.uk/carers-allowance

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

Citizens Advice

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

England

Helpline **0800 144 8848** www.citizensadvice.org.uk

Scotland

Helpline **0800 028 1456** www.cas.org.uk

Wales

Helpline **0800 702 2020** www.citizensadvice.org.uk/wales

Disability and Carers Service

Tel 0800 587 0912

Textphone 0800 012 1574

<u>nidirect.gov.uk/contacts/disability-and-carers-service</u> Manages Disability Living Allowance, Attendance Allowance, Carer's Allowance and Carer's Credit in Northern Ireland. You can apply for these benefits and find information online or through its helplines.

GOV.UK

www.gov.uk

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

Local councils (England, Scotland and Wales)

Your local council may have a welfare rights unit that can help you with benefits. You can also contact your local council to claim Housing Benefit and Council Tax Reduction, education benefits, and for help from social services (the Social Work department in Scotland).

You should be able to find your local council's contact details online by visiting:

England

www.gov.uk/find-local-council

Scotland

www.cosla.gov.uk/councils

Wales

gov.wales/find-your-local-authority

Macmillan Benefits Advice Service (Northern Ireland)

Tel 0300 1233 233

Money Advice Scotland

<u>www.moneyadvicescotland.org.uk</u> Use the website to find qualified financial advisers in Scotland.

NiDirect

<u>www.nidirect.gov.uk</u> Has information about benefits and public services in Northern Ireland.

Unbiased.co.uk

Helpline **0800 023 6868**

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

British Red Cross

Tel 0344 871 11 11

www.redcross.org.uk

Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

Disability Rights UK

Tel 0330 995 0400 (not an advice line)

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.

Motability Scheme

Tel 0300 456 4566

www.motability.co.uk

The scheme enables disabled people to exchange mobility allowances they have as part of benefits (including the enhanced rate mobility component of Personal Independence Payment) to lease a new car, scooter or powered wheelchair.

Scope

Helpline **0808 800 3333**

Textphone Use Type Talk by dialling **18001** from a textphone followed by **0808 800 3333**.

www.scope.org.uk

Offers 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

Teenage Cancer Trust

Tel 0207 612 0370

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 0208 772 9900

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 1602

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

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.

Live Through This

www.livethroughthis.co.uk

A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produces resources about LGBT cancer experiences. LTT runs a peer support group with Maggie's Barts.

Support for carers

Carers Trust

Tel 0300 772 9600

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 **0808 808 7777**

www.carersuk.org

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

Support with sight loss

Royal National Institute of Blind People (RNIB)

Helpline **0303 123 9999** <u>www.rnib.org.uk</u> Offers support and advice to blind and partially sighted people in the UK.

Support with hearing loss

RNID

Helpline 0808 808 0123

Textphone Call 18001 followed by 0808 808 0123

SMS 0736 026 8988

www.rnid.org.uk

Offers support and practical advice to people in the UK with hearing loss and tinnitus.

Advanced cancer and end of life care

Hospice UK

Tel **0207 520 8200**

www.hospiceuk.org

Provides information about living with advanced illness. Also provides free booklets and a directory of hospice services in the UK.

Marie Curie

Helpline **0800 090 2309**

www.mariecurie.org.uk

Marie Curie nurses provide free end of life care across the UK. They care for people in their own homes or in Marie Curie hospices, 24 hours a day, 365 days a year.

Your notes and questions

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 are 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, Prof Tim Iveson, Consultant Medical Oncologist.

With thanks to: Michelle Buono, Clinical Nurse Specialist; Emma Chalmers, Clinical Educator, Cancer Services; Emma Gudgeon, Occupational Therapist; Dr Chris Jenkins, Consultant Oncologist; Dr Ollie Minton, Consultant Oncologist; Emily Stowe, Clinical Specialist Physiotherapist; and Jackie Whigham, Clinical Nurse Specialist.

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**

Sources

Below is a sample of the sources used in our fatigue information. If you would like more information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

R Bhargava, A.Fabi, S.Fatigoni et al. Cancer related fatigue: ESMO Clinical Practice Guidelines for diagnosis and treatment. 2020. European Society of Medical Oncology. Available from esmo.org/guidelines/guidelines-bytopic/supportive-and-palliative-care/cancer-related-fatigue [accessed July 2022].

Scottish Partnership for Palliative Care steering group. Scottish Palliative Care Guidelines. Weakness/Fatigue. 2019. NHS Scotland. Available from www.palliativecareguidelines.scot.nhs.uk/guidelines/symptom-control/ weakness-fatigue.aspx [accessed July 2022].

Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are 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 are here 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.

5 ways you can help someone with cancer

1. Share your cancer experience

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

2. 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.

3. 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?

4. Raise money

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

5. Give money

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

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

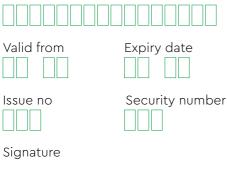
Fmail

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



Date

Do not let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us at no extra cost to you. All you have to do is tick the box below. and the tax office will give 25p for every pound you give.

I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations. until I notify you otherwise.

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Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box.

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.

If you would rather donate online go to 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. This feeling is not helped by rest.

The booklet talks about the causes and effects of cancer-related fatigue and things you can do to help manage it. It also has information about feelings, practical issues and money.

At Macmillan, we give people with cancer everything we've got. If you are diagnosed, your worries are our worries. We will help you live life as fully as you can.

For information, support or just someone to talk to, call <u>0808 808 00 00</u> or visit <u>macmillan.org.uk</u> 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 <u>18001 0808 808 00 00</u>, or use the NGT Lite app.

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