

Managing fatigue

A guide to making the
most of your energy



**Marie
Curie**

* Calls are free from landlines and mobiles. Your call may be recorded for training and monitoring purposes.

Introduction

If you have fatigue, this booklet may be helpful for you. It's aimed at people with a life-limiting or terminal illness and may be helpful at any stage of your illness.

Fatigue is a feeling of extreme tiredness. We know that fatigue can have a big impact on your life. There are lots of people who can support you, and there are things you can do yourself to make it easier to live with.

Your family and friends may also find this booklet useful. If you have any questions or concerns about fatigue, speak to your healthcare team who will be able to support you. You can also contact our Support Line on **0800 090 2309*** and speak to a trained officer or registered nurse for practical information and emotional support.



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What is fatigue?

Fatigue is a feeling of extreme tiredness, weakness or lack of energy. It's different to normal tiredness. It doesn't go away after rest or getting a good night's sleep.

Speak to your health professional if you think you have fatigue. They can find out what's causing it and recommend the best ways to manage it. See pages 8 to 10 on how to get support.



Philip Hardman/Marie Curie

Living with fatigue

People sometimes describe having fatigue as being 'wiped out', or 'hitting a brick wall' when they run out of energy.

Fatigue can affect all areas of your life. If you have fatigue, you might experience:

- feeling drained and as if you have no energy
- difficulty sleeping at night
- problems with your short-term memory
- feeling like your arms or legs are heavy
- difficulty completing daily activities, such as washing and dressing
- difficulty concentrating and making decisions
- loss of interest in sex
- lack of motivation
- not enjoying the things you usually enjoy.

It can be really frustrating and upsetting to have fatigue, especially when it stops you doing the things you want to do.

Some people feel guilty about not being able to do as much as they could before, but it's important to remember that fatigue isn't your fault.

What causes fatigue?

We don't know exactly what causes fatigue but there are lots of different things that make it more likely. There might be more than one thing that's causing your fatigue. Fatigue can be caused by long-term illnesses such as cancer, multiple sclerosis, heart failure and kidney failure.

Fatigue can also be caused by things that can be treated, or things which may only last for a short time, including:

- treatments such as chemotherapy, radiotherapy and surgery
- eating less because you've lost your appetite
- not being as active as before
- side effects of treatments or illness, such as anaemia (low red blood cell count)
- anxiety and depression.

Speak to your doctor or nurse and they will be able to find out if you have any reversible causes of fatigue, and recommend ways to treat them.

“At first, you feel regret, guilt and frustration that you can't do as much as you used to be able to. But you can accept it and find a new starting point.”

Colin, living with fatigue

Explaining fatigue to other people

It can be hard to explain fatigue to other people. Some people feel guilty or ashamed about having fatigue. Try to remember, it's not your fault. Fatigue is 'invisible', so people might not know that you have it. Explaining to others how you're feeling can help them to understand what to expect of you and how to support you.

Think about who it would be helpful to talk to, such as:

- family
- friends
- health professionals
- colleagues or your employer
- children.

Try explaining that you only have limited amount of energy and that you need to use it doing the things that are most important to you.

This can also be a good opportunity to ask for help with some of the things you're not able to do anymore, such as shopping, driving or doing housework.

“Speaking to other people who have fatigue and know what it feels like is really helpful. When I come to the gym at the hospice, I don't need to explain what it's like to the other people there. They get it.”

Colin, living with fatigue



Philip Hardman/Marie Curie

Getting support with fatigue

If you need extra help to manage your fatigue, there are lots of professionals who can support you. Your GP, hospital team or local hospice will be able to refer you to other professionals.

Your GP or hospital doctor

Your GP or hospital doctor can help find out what's causing your fatigue, prescribe any medicines that might help, and recommend ways to manage it.

Physiotherapists

Physiotherapists can help you to plan your daily activities in a way that saves your energy. If you want to do more activity, physiotherapists can show you ways to exercise safely. They can also help you manage other symptoms including breathlessness.

Occupational therapists

Occupational therapists (OTs) can help you to plan your activities so that you can do the things that are most important to you. They can recommend different techniques, equipment or changes to your home like hand-rails, which would make it easier to carry out activities.

Hospices

If you're living at home, you can still have treatment and support in a hospice. At many hospices, you can come into the day therapy unit. This is a part of the hospice for people who aren't staying there. Healthcare professionals run sessions to help you manage your symptoms. Some hospices run group sessions where you can learn about how to manage fatigue, anxiety and breathlessness. Ask your doctor if there any sessions you can attend at your local hospice. Hospices also have wards where you can stay for a longer period and get extra support to manage your symptoms. Read more about Marie Curie Hospices on page 28.

Clinical nurse specialists

Clinical nurse specialists are experts in particular illnesses such as cancer and heart failure. They can give advice on how to manage fatigue, and give you information about support groups and classes in your local area.

Palliative care nurses

Palliative care nurses are part of a hospice or hospital team. They are specialists in managing symptoms and supporting people with a terminal illness. Palliative care nurses work in hospices and hospitals and can also visit you at home.

Social worker

Social workers can help you to find out if you can get any benefits or carers who can help you at home. They can also arrange respite care for any friends and family members who are looking after you.

Other professionals

You might find it helpful to talk to other professionals such as counsellors, psychologists, music and arts therapists, and spiritual advisors. They are trained to talk to you about what's most important to you and support you with any worries, fears and concerns. They can sometimes be accessed through a hospice. Or you can ask your doctor about what services are available in your area.



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What can you do to manage fatigue?

There are lots of things you can do to manage fatigue. You might need to start thinking differently about how you do things. Planning your activities can help you to make the most of your energy. Doing some physical activity and sleeping well can also help to boost your energy levels.

It can be helpful to imagine that all the energy you have is stored in a battery. The battery only has a limited amount of charge before you need to rest. This means that there is only a limited amount of energy to do all the things you want to do.

Making the most of the energy you have

The five Ps – prioritising, planning ahead, pacing, positioning and permission – are a good way to make the most of the energy you have.

Prioritising

If you don't have enough energy to do all the things you used to do, think about the things that are most important to you. Different things are priorities for different people. For some people spending time with friends is a priority. For others going to work or doing hobbies is most important.

Make a list of the activities you want to do and select the ones that are most important. Try to include enjoyable and relaxing activities as well as work and chores.

“I didn’t go out at all but now I go to the hairdresser every week and it is great for me. I need to use a wheelchair, but I can get out the house again and have my hair done.”

Person living with fatigue

Planning ahead

Think about all the activities you want to do during the week ahead. Spread your tasks throughout the week rather than doing them all in one day. Try to avoid having two busy days together. If you have a very busy day, plan a rest for the day after.

Each day, think about how to spread your activities throughout the day. This allows you to recover after doing each task.

Some people find it helpful to use a diary to plan ahead. There’s a diary you can use on page 24. You can write down what activities you do, and you can also track your energy levels throughout the day. This allows you to plan activities for when you have the most energy.

“Things that require mental energy such as reading a book or being on the computer can be just as taxing as physical activity like walking round the block.”

Ann, physiotherapist

What can you do to manage fatigue?



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Pacing activities

Many people find it hard to slow down when they used to move at a faster pace. Try to take your time when you're doing activities. Remember that you may have to ask for help to do some tasks and that is OK. Listen to your body and try to understand your limits.

“I thought I couldn't do anything any more, but the occupational therapist helped me and showed me there was still lots I could do. I just do a wee bit at a time, but I am not so scared of everything now.”

Person living with fatigue



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Positioning

Getting into a different position can save you energy. Consider how you could do your activities in an easier way. For example, sitting down to chop vegetables or sort out your laundry uses less energy than doing it standing up.

Permission

Give yourself permission to do things differently to how you did them before. This might involve asking for help with activities you used to do by yourself. Take rests and have naps if needed.

Even if you plan ahead you might not always have enough energy to do the things you want to do. Be kind to yourself and don't worry if you don't get through all your activities in a day.

“I have a nap in the afternoon. I know that I’ll have around 45 minutes sleep after lunch and it helps. If I’ve got a lot on, I might have to miss the nap and then I’ll be more tired in the evening. I had to give myself permission to do this and not feel guilty about it.”

Colin, living with fatigue

Physical activity

It's good to stay as active as possible without overdoing things. It might seem strange because it takes energy to do exercise, but being active can actually give you more energy. Physical activity could be things like walking, gardening or swimming. Or it could be moving your arms and legs in bed or in a chair. Do something that you enjoy. A physiotherapist can help you to find the best activities for you.

When you're doing physical activity:

- You should still be able to talk in short phrases as you exercise. If you can't do this, slow down until you recover your breath.
- Try controlled breathing exercises to manage your breathing while you exercise.

In some areas, doctors can prescribe exercises classes. These might be run at a local gym or in a hospital. Some hospices also run sessions where you can use the gym. Ask your doctor or physiotherapist if there are exercise classes you can join in your area.

“Just doing that exercise every week, I seem to brighten up just thinking about going. I think it's meeting other people too that helps me.”

Person living with fatigue

Sleeping well

Sleeping well can help to recharge the batteries. Here are some tips on how to get a good night's rest.

During the day

- Doing some physical activity during the day can help you to sleep at night.
- Following a routine, for example getting up and going to bed at the same time every day, may improve your sleep at night.

Before bed

- Try relaxing before bed. Listening to music or trying relaxation techniques such as deep breathing might help. Some people find a bath helpful if they have enough energy.
- Doing the same routine each night can help you feel ready for sleep.
- Avoid caffeine, nicotine and alcohol in the evening.

In bed

- Set up your bed in a room that's quiet, calm and at a comfortable temperature.
- If it's noisy, try using earplugs.
- Try not to use electronic devices such as tablets and smartphones in bed.
- If you're having trouble getting to sleep because of worries and concerns, it can help to have a pen and paper beside your bed, so you can write things down and deal with them in the morning.

Eating well

Food is the fuel for your body. Eating a healthy diet can help to maintain your energy levels. Having an illness can affect your appetite. If you're finding it difficult to eat, speak to your doctor or nurse and they can refer you to a dietitian.

If you're finding it tiring to eat big meals, try having smaller portions and snacks throughout the day.

If you don't have the energy to prepare meals for yourself, you could ask a friend or family member to help. You can also ask your doctor or social worker about getting healthy meals delivered to your home.

Coping with feelings

Living with fatigue can be very difficult. It might make you feel depressed, frustrated, anxious or guilty. If you're finding it hard to cope, try talking to someone you trust about how you're feeling. This could be a friend, family member or your doctor or nurse.

You can also contact our free Support Line on **0800 090 2309*** for practical information and emotional support.

Your doctor or nurse can prescribe medicines to help, and they can refer you to another professional for more support. A counsellor or psychologist can help you understand and work through your feelings.

What can you do to manage fatigue?

Counselling is a talking therapy that is sometimes free at hospices, hospitals or GP surgeries. If this is something you want to try, ask your doctor or nurse. They can let you know what talking therapies are available locally and can help you decide which treatment is best for you. For more information about free counselling services speak to your GP.

You may also be able to get private counselling, which you have to pay for. For more information, ask your doctor or visit the British Association of Counselling and Psychotherapy website to find a qualified counsellor near you (see page 29).

Having depression or anxiety can also make your fatigue harder to manage. Getting support for depression and anxiety can help to improve your fatigue too.

Relaxing

Finding ways to relax can improve your rest and help you to manage your fatigue. Try to find time to relax every day. You might find it helps to do breathing exercises, listen to music or an audiobook, spend time outside, have a bath or try meditating.

Complementary therapies

Some people find that complementary therapies such as acupuncture, reiki and massage make them feel more relaxed, and this can help to manage fatigue. Speak to your doctor or nurse before you have complementary therapy. They can advise you on the safety of different types of therapy. Some complementary therapies might not be suitable or safe for you, depending on your health condition and treatment.

Some complementary therapies are provided free of charge by the NHS, but they are not always available. Speak to your doctor or nurse about what's available in your area. Your local hospice or a local support group may also offer free or reduced cost therapies. You can also get complementary therapies privately, but you will have to pay for these. Private therapists can be expensive, so it's worth checking the cost first.

It's also important to tell the complementary therapist about your medical condition and any treatments that you've had or are having. They can make sure the therapy is suitable for you.



For more information about complementary therapies visit mariecurie.org.uk/complementary-therapies

Fatigue towards the end of life

Sometimes people feel more fatigued as their illness progresses and they approach the end of their life. People can still use all the techniques that have helped them before such as pacing and planning ahead. The things that are most important to someone might change over time and they might prioritise doing different tasks.

Towards the end of life, everyday activities may become too tiring to do. Needing to sleep or rest more than usual is normal.



You can find out more about what to expect at mariecurie.org.uk/what-to-expect or contact our free Support Line on **0800 090 2309***.



Layton Thompson/Marie Curie

Supporting someone with fatigue

If your friend or family member has fatigue, there are things you can do to support them:

- Understand that your relationship to the person might change as they may need you to help them with more activities.
- Talk to them about what activities are most important for them to do.
- Support them to do those activities at their own pace.
- Support them to do things independently if they can. Be aware that how much they can do might change over time.
- Be prepared that you might need to take on more tasks such as cooking and cleaning. If you need extra help with this, speak to your doctor or social worker (see pages 8 to 10).
- Encourage the person to talk about any fears or worries they have.

“My wife wouldn’t let me do anything at all – she was scared I would make myself worse. At the hospice they said to her it was OK as long as I felt OK. Now I make her a cup of tea and it’s good for me.”

Person living with fatigue

Supporting someone with fatigue

Supporting someone with a terminal illness can be rewarding but it can also be very challenging. If you need extra support, speak to your GP about how you're feeling. They can support you with your own health, refer you to a social worker (see page 10) or recommend support groups in your local area.



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Fatigue diary and weekly planner

Keeping a diary of your energy levels can help you to know if you feel more tired at certain times of the day, or after doing certain activities. This can help you to plan your activities so that you have more energy.

Fatigue diary

Every day, write down any activities you do throughout the day and how tired you feel. Include resting as an activity. You can rate how tired you're feeling on a scale of 0-10. 10 is the most tired you can imagine and 0 is not tired at all.

Day and date	Early morning	Late morning	Early afternoon	Late afternoon	Early evening	Late evening	Overnight
Monday _____	Example: <i>Had a shower 4</i>						
Tuesday _____							
Wednesday _____							
Thursday _____							
Friday _____							
Saturday _____							
Sunday _____							

You might find it useful to share this with your doctor or nurse. It can also be helpful to show it to your family and friends, so they can see how fatigue affects you.

Weekly planner

Write down the things you **need** to do this week:

Write down the things you **want** to do this week. Include activities you find enjoyable and relaxing:

Ask yourself four things about any activity you are going to do:

- Do I want to do it?
- Do I need to do it?
- Is there an easier way to do it?
- Am I happy for someone else to do it for me?

Managing fatigue

Look at your fatigue diary to see when you might be likely to feel tired. Try and plan your activities so that they're spaced out throughout the week. It might be helpful to plan a rest after any activities that make you feel very tired.

Day and date	Morning	Afternoon	Evening
Monday _____	Example: <i>Rest</i>	<i>Pick up K from school</i>	<i>Watch a film</i>
Tuesday _____			
Wednesday _____			
Thursday _____			
Friday _____			
Saturday _____			
Sunday _____			

You might find it helpful to share your weekly planner with your friends and family, so they can support you with your activities.

How Marie Curie can help

Marie Curie is here for anyone with an illness they're likely to die from, and those close to them. Whatever the illness, wherever you are, we're with you to the end.

Marie Curie Support Line

0800 090 2309*

Our free Support Line is for anyone with an illness they're likely to die from and those close to them. Our team, including nurses and specialist Energy Support Officers, offers practical and emotional support on everything from symptom management and day-to-day care to financial information and bereavement support. Our Support Line is available in over 200 languages, or via webchat at mariecurie.org.uk/support. Open between 8am to 6pm from Monday to Friday, and 11am to 5pm on Saturday.

Marie Curie Companions

Companion volunteers focus on what's important to you and those close to you. It might be accompanying you to appointments, being there to listen to how you're feeling without judgment, or stepping in so family or carers can take a break. Companions provide the emotional and practical support you want - at home, in hospital or over the phone.

mariecurie.org.uk/companions

Marie Curie Telephone Bereavement Service

Get ongoing bereavement support over the phone from the same volunteer. You can access up to six sessions of 45 minutes. We can help if your bereavement was expected, happened recently or was some time ago.

mariecurie.org.uk/bereavement

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Marie Curie Online Community

Our Online Community is a space for you to share thoughts, feelings and experiences. It's moderated by the Marie Curie Support Line team, who can also help answer your questions.

community.mariecurie.org.uk

Marie Curie Hospice care where it's needed

Our hospices

Our hospices help people with any illness they're likely to die from, and the people close to them, receive the support they need. From medical and physical support to psychological and emotional care, whatever your illness, at whatever stage of the journey, we help you to live the best life possible, right to the end.

mariecurie.org.uk/hospices

Hospice care at home

Our nurses, healthcare assistants and other healthcare professionals bring the clinical, practical and emotional help you need to you, in the comfort of your own home. And we offer support to the people close to you too - from reassurance and practical information to letting them take a break.

mariecurie.org.uk/nurses

Looking for more information?

If you found this booklet useful, we have free information available online at mariecurie.org.uk/support or to order at mariecurie.org.uk/publications

Useful organisations

Macmillan Cancer Support

0808 808 00 00

[macmillan.org.uk](https://www.macmillan.org.uk)

Information and support for people living with cancer in the UK.

British Association for Counselling and Psychotherapy

01455 883300

[bacp.co.uk](https://www.bacp.co.uk)

Find detailed information about different types of therapy and counselling. You can also search for a therapist near you.

About this information

This booklet was produced by Marie Curie's Information and Support team. It has been developed with people affected by terminal illness, and health and social care professionals.

If you'd like the list of sources used to create this information, please email review@mariecurie.org.uk or call the free Marie Curie Support Line on **0800 090 2309***.

Notice

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Did you find this information useful?

If you have feedback about this booklet, please email us at review@mariecurie.org.uk or call the free Marie Curie Support Line on **0800 090 2309***.

Marie Curie

Marie Curie is the UK's leading end of life charity. Whatever the illness, wherever you are, we're with you to the end.

0800 090 2309*

Marie Curie provides free support over the phone in over 200 languages, and via webchat, to anyone with an illness they're likely to die from and those close to them.

Our team, including nurses and specialist Energy Support Officers, offers practical and emotional support on everything from symptom management and day-to-day care to financial information and bereavement support. Visit mariecurie.org.uk/support

We also have an Online Community where you can share thoughts, feelings and experiences at community.mariecurie.org.uk

We can't do it without you

Our free information and support services are entirely funded by your generous donations. Thanks to you, we can continue to offer people what they need, when they need it.

To donate, visit mariecurie.org.uk/donate

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