

Managing fatigue when you have a terminal illness

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

This booklet is about managing fatigue while living with a terminal illness, and towards the end of life. It may also be helpful if you're supporting someone with a terminal illness.

Fatigue is more than feeling tired. It can affect your body, thoughts and emotions. It's a common symptom when you have a terminal or life-limiting illness.

Fatigue can feel worrying or frustrating. Some people feel confused about why it's happening or guilty for needing more rest. If you feel this way, you're not alone. And there are things you could try that may make fatigue easier to live with.



Philip Hardman/Marie Curie

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What fatigue feels like

Fatigue is a deep, ongoing tiredness that does not always improve with rest or sleep. It can affect people in different ways, and at different points in their illness.

You might:

- feel very tired, exhausted, or like you have no energy
- feel physically weak, or like your body feels heavy
- get tired quickly and need to rest more, even during small tasks
- sleep more
- find it hard to concentrate or remember things
- feel low, anxious, irritable, or have other difficult emotions.



Philip Hardman/Marie Curie

Managing fatigue when you have a terminal illness

Fatigue can change from day to day, and may be worse at certain times of the day.

It can limit how much you can do and may affect your independence. It may affect different areas of your life, such as work, hobbies, and spending time with people important to you. Even things like walking, washing or dressing may feel exhausting.

These life changes may affect how you feel about yourself. They can be really difficult to deal with, both emotionally and practically. Some people find fatigue one of the hardest symptoms to cope with.

There are ways to manage fatigue, and what works will be different for everyone. See page 8 for some ideas on how to manage fatigue.

“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

Causes of fatigue

Lots of things can cause fatigue when you're living with a terminal illness. It can be hard to know the exact cause, and there is usually more than one. These can change as your illness or treatment changes.

Effects of your illness

Your body uses more energy to cope with illness. Your illness may also cause changes in your body that can make you feel more fatigued. For example, changes to hormones, some organs not working as well, or symptoms like pain and breathlessness.

Side effects of treatments

Treatments such as chemotherapy, radiotherapy, immunotherapy or surgery can cause fatigue. The fatigue may continue for months or longer after treatment has finished. Some medicines can make you feel sleepy, drowsy or less alert. These include strong pain medicines (such as opioids), medicines for anxiety, and anti-sickness medicines.

Speak to your doctor or nurse if you think your treatment could be causing your fatigue.

Eating and drinking less

Lots of people living with a terminal illness eat and drink less. This may be caused by having a lower appetite, feeling sick (nausea), changes in taste, or problems swallowing.

Eating and drinking less may mean you may have less energy. But it's usually not the only thing causing your fatigue. Speak to your doctor or nurse if you have questions or worries about eating and drinking.



For more information about eating and drinking problems, visit mariecurie.org.uk/eating-drinking

You can also call the free Marie Curie Support Line on **0800 090 2309*** or email [**support@mariecurie.org.uk**](mailto:support@mariecurie.org.uk).



Philip Hardman/Marie Curie

Sleep, rest and activity levels

Fatigue may be affected by how much sleep you get, the quality of your sleep, and how active you are.

Sitting or lying down for long periods may, over time, mean exercise and daily tasks become more difficult. But doing lots of things without having some rest may make you feel very fatigued. It's important to find the right balance for you. See page 8 for information about how to make the most of your energy.

Infections and other conditions

Different conditions caused by your illness or treatment may cause fatigue. For example infections, or low iron or red blood cell levels (anaemia). Your doctor or nurse may be able to treat some of these causes.

How you feel mentally and emotionally

Depression, anxiety, and feeling worried, sad or stressed may cause fatigue, or make it worse.

Managing fatigue

There is no single treatment that takes away fatigue completely. But small changes may help you use your energy in ways that matter most to you. And there may be ways the people around you or professionals can support you.

Focus on what matters most to you

You might not have enough energy to do everything you used to. Focus on things most important to you, such as spending time with friends and family, or doing something you enjoy.

You could also make a to-do list. Then decide what needs to be done, what you could ask others to do, what can wait, and what could be left.

Pay attention to how your body feels

- Rest when you need to, even if it feels earlier than you expect.
- Try not to push yourself to keep going when you are exhausted.
- Accept that your energy may change from day to day.
- Allow yourself to have days doing very little or nothing, if that's what your body needs.

“I believe his fatigue was helped by doing things he enjoyed, and having a natural disposition to identify when he needed to rest.”

Mary, whose father had fatigue

Balance activity and rest

You could:

- allow time for rest after each activity
- spread activities across the day or week
- plan a rest day after a particularly busy day
- stop before you feel very tired or exhausted.

Pacing yourself or doing things more slowly can feel difficult, especially if you're not used to it. But it can be a helpful way to manage having limited energy.

Change how you do tasks

Small changes may help save energy. You could:

- sit down while doing tasks
- gather everything you need before starting a task
- use mobility aids such as shower chairs or walking aids
- use long-handled cleaning tools and long shoe horns to avoid bending and stretching
- ask someone else to help with tasks such as shopping or cleaning.

Managing fatigue when you have a terminal illness

An occupational therapist (OT) can help with aids, equipment, and changes to tasks. You could ask your GP, district nurse, council or Health and Social Care Trust to refer you to an OT.

“My mother found it incredibly hard having to adjust to using a wheelchair. She was young and fit and that was hard for her to accept. But without it, she would have struggled to do anything in the last two months of her life.”

Clara, whose mother had fatigue

Use a fatigue diary and planner

You could try keeping a diary of how tired you feel during activities, and at different times of the day. This may help you work out what affects your fatigue most, and plan your activities and rest around what works for you.

See page 24 for a fatigue diary and planner you could use.

Gentle movement or exercise

Some people find that some level of movement helps with stiffness, comfort, mood and energy levels. For example short walks, stretching or moving in bed or a chair, or activities such as gardening.

Only do what feels manageable. This will be different for everyone. And not everyone finds physical activity possible.

Your doctor or nurse can advise what is safe for you. And they could refer you to a physiotherapist, who can help you find movements that fit with your needs.

Eating and drinking

Lots of people with a terminal illness eat and drink less, which can affect energy levels. You could try:

- eating little and often if large meals feel too much
- choosing foods you enjoy – these might change over time
- drinks or snacks that give you lots of calories and nutrition, instead of meals.

Wanting to eat less is natural towards the end of life. If you do not feel like eating, try not to worry. Focus on food and drink you enjoy. Your doctor or nurse can help if you or the people around you have questions or concerns.



For more information about eating and drinking less at the end of life, visit mariecurie.org.uk/eat-drink-end-of-life

Sleep and rest

- Rest during the day if you need to. Short naps may be better than long ones.
- Try to sleep somewhere that's a comfortable temperature, quiet, and not too bright.
- Avoid looking at screens for at least an hour before bed.
- Do something that relaxes you before going to bed – for example reading a book, or listening to music.
- Try getting up and going to bed at the same time each day.
- Avoid having caffeine, nicotine, alcohol or large meals close to when you go to bed.
- Tell your doctor or nurse if any symptoms affect your sleep, such as pain, breathlessness, or anxiety.

Complementary therapies

Some people find complementary therapies relaxing or comforting. These may include:

- massage
- reiki
- acupuncture.

These therapies do not treat the cause of fatigue. But they may help you feel calmer or more comfortable. Always talk to your doctor or nurse before trying any therapy to check it is safe for you.



iStock

Talking about fatigue

Fatigue is not always visible, and it can be difficult for people to understand. This can mean people may not realise how much it affects you.

Talking about how fatigue makes you feel and how it affects your life, can help people understand changes they may have noticed. It can also be an opportunity to ask for help if there are things you're finding difficult. Having these honest conversations can ease stress for you and others.

“I don't think I recognised at the time that deep-rooted fatigue meant even minor day-to-day tasks were incredibly hard for him.”

Lynn, whose husband had fatigue



Philip Hardman/Marie Curie

Getting support from your doctor or nurse

You can also speak to your doctor or nurse about your fatigue. They can check whether there is anything causing it that could be treated. For example, side effects from a medicine or an infection.

They may make other suggestions to help you manage your fatigue. And they may be able to refer you for further support. For example, occupational therapy, local fatigue groups, or emotional support.



For more information about the professionals who could support you, visit mariecurie.org.uk/palliative-care-team

“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

The emotional impact of fatigue

Fatigue can affect how you feel about yourself and your life. You might feel:

- frustrated or angry about not being able to do what you'd like to
- guilty about needing help or rest
- worried about running out of energy
- sad about losing your independence
- lonely or isolated if you cannot socialise, or if others do not understand how you are feeling.

Looking after your emotional wellbeing

There may be times you feel unable to do much, or anything at all – this is OK. Acknowledging this, and giving yourself permission to do nothing, may help with feelings of stress or worry. During these times, you could find something you enjoy doing that helps you relax.

You might also find it helpful to:

- talk about how you feel
- try breathing or relaxation exercises
- spend time outdoors or by a window if you can.

You could talk to a family member, friend, faith leader, or someone in your healthcare team about how you're feeling.

The emotional impact of fatigue

If you'd like further support, your doctor or nurse may be able to refer you to different services. For example, a counsellor or psychologist can help you to understand your feelings, and find ways to cope. Or you could look for private counselling, which you'd need to pay for. See page 30 for where to find a counsellor.

Your healthcare team, local hospital, or hospice may have a chaplaincy or spiritual care service. You do not need to be religious to have this support.



Our free Companion over the phone service provides ongoing emotional support with the same trained volunteer each week, no matter where you live in the UK or whether you've accessed support from Marie Curie before. Ask about the service at **mariecurie.org.uk/book-a-call** or call the free Marie Curie Support Line on **0800 090 2309***.



Marie Curie's Online Community gives you the chance to connect with people in similar situations to you. You may be able to speak with others who understand what fatigue feels like. Visit **community.mariecurie.org.uk** to join Marie Curie's Online Community.

Planning for future care

Thinking about the future can help you feel more in control and less worried. You might want to think about:

- where you would prefer to be cared for
- who you want to be involved in decisions
- what brings you comfort or meaning
- how you would like to use your energy.

Your healthcare team can help you make plans that feel right for you.



We have more information on planning for future care in our free booklets, **Planning ahead** and **Getting care and planning for the future when you're LGBTQ+**. Order or download a free copy at mariecurie.org.uk/publications or call the free Marie Curie Support Line on **0800 090 2309***.

Fatigue towards the end of life

Fatigue usually gets worse as an illness progresses, but this is different for everyone. For example, some people need to go to bed earlier, or need help with things they previously did themselves.

Many people sleep more and eat less towards the end of their life. They may have very little energy to talk or move. These changes are a natural part of dying, and do not usually cause the person pain or distress.

There may be a point towards the end of life when trying to manage fatigue is not the best option for someone. For example, trying to give them food and water may be uncomfortable for them.

Fatigue may even give some comfort at this stage. If they are more sleepy, they may be less aware of difficult symptoms like pain or anxiety. This point is different for everyone, and may be in the last weeks, days, or hours of life.

It's OK if you or the people around you feel worried or scared if your fatigue gets worse. Your doctor or nurse should help keep you comfortable, and support you all during this time. You could speak to them if you have any questions or worries about the end of life.

Managing fatigue when you have a terminal illness

- ▶ If you'd like to speak to someone about how you're feeling, call the free Marie Curie Support Line on **0800 090 2309*** or email **support@mariecurie.org.uk**
- ▶ We describe different symptoms towards the end of life on our website at **mariecurie.org.uk/end-of-life** and in our booklet, **What to expect towards the end of life**. Order or download a free copy at **mariecurie.org.uk/publications** or call the free Marie Curie Support Line on **0800 090 2309***.



Phil Hardman/Marie Curie

Supporting someone with fatigue

Supporting someone with fatigue can be difficult. Fatigue can be hard to understand if you have not experienced it or known anyone who has.

It can be worrying to see someone sleep more, stop doing things they enjoy, and even stop doing daily tasks that seem small. Some things in your relationship may change, and you may find you need to do more. This may affect your own energy levels, work, and personal life. You might be understandably confused, frustrated or worried.

You may wonder:

- Is this normal?
- Am I letting them rest too much?
- Should I encourage them to eat, move or stay awake?
- Does this mean they are getting worse?

Try to remember that fatigue is a common and natural part of living with a terminal illness. As an illness progresses, the body needs more energy to cope, and people often rest and sleep more. This is not caused by a lack of effort or motivation.

Fatigue may get worse towards the end of life. See page 19 for more information about what to expect at this stage.

How you can help

You can support someone with fatigue by:

- finding out how fatigue makes them feel, so you can better understand what day-to-day life is like for them
- understanding that energy levels can change from hour to hour or day to day
- accepting that fatigue will happen, even when care and treatment are good
- letting the person rest when they need to, without pressure or guilt
- offering help, but respecting the person's choices about what they can manage
- focusing on comfort and what matters most, rather than trying to do everything
- letting them know they can talk to you about how they're feeling
- suggesting ways to spend time together that will not need much energy
- explaining their fatigue to others who may not see or understand how it affects them.

“Derek and I got a lot of pleasure in bingeing TV series with snacks and tea, and sharing something we both loved.”

Lynn, whose husband had fatigue

Getting support for yourself

Caring for someone with a terminal illness can be physically and emotionally exhausting. It's important to consider your own needs, and whether you'd like emotional or practical support too.

The nurse, doctor or another member of the health or social care team may be able to help by:

- helping with tiring or practical tasks
- encouraging rest without pressure
- answering questions, and talking about any worries.

You could ask if they know of any local support services. For example, community or voluntary groups, or services at a local hospice or hospital. See page 30 for some organisations that may be able to help.



Our free Companion over the phone service provides ongoing emotional support with the same trained volunteer each week, no matter where you live in the UK or whether you've accessed support from Marie Curie before. Ask about the service at mariecurie.org.uk/book-a-call or call the free Marie Curie Support Line on **0800 090 2309***.

Fatigue diary and weekly planner

You could try keeping a diary of your energy levels. It can help you see if your fatigue is worse at certain times, or after particular activities. This might help you plan activities, or avoid ones that make you feel fatigued.

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.

You might find it useful to share this with your doctor or nurse. It can also be helpful to show it to others around you, such as family and friends. This might help them see how fatigue affects you.

Day and date	Early morning	Late morning	Early afternoon	Late afternoon	Early evening	Late evening	Overnight
Example:	<i>Had a shower</i> 4	<i>Made breakfast</i> 6	<i>Weekly shop</i> 9	<i>Rest</i> 4	<i>Cooked dinner</i> 7	<i>Watched a film</i> 2	<i>Rest</i> 0

Fatigue diary and weekly planner

Day and date	Early morning	Late morning	Early afternoon	Late afternoon	Early evening	Late evening	Overnight
Monday _____							
Tuesday _____							
Wednesday _____							
Thursday _____							
Friday _____							
Saturday _____							
Sunday _____							

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?

Fatigue diary and weekly planner

Look at your fatigue diary to see when you might be likely to feel tired. Try and plan your activities so 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
Example: _____	<i>Rest</i>	<i>Pick up K from school</i>	<i>Watch a film</i>
Monday _____			
Tuesday _____			
Wednesday _____			
Thursday _____			
Friday _____			
Saturday _____			
Sunday _____			

It could be helpful to share your planner with people around you, so they can support you with different 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.

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

* Your call may be recorded for training and monitoring purposes.

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

British Association for Counselling and Psychotherapy

01455 883300

bacp.co.uk

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

Mind

0300 123 3393

mind.org.uk

Mind has online information about mental health and support. You can speak to people on the phone for mental health information and support, and benefits and legal information.

Carers UK

0808 808 7777

carersuk.org

Carers UK provides information and support to people caring for relatives and friends. They have a directory of local support services for carers.

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

The information in this publication is provided for the benefit and personal use of people with a terminal illness, their families and carers.

This information is provided as general guidance for information purposes only. It should not be considered as medical or clinical advice, or used as a substitute for personalised or specific advice from a qualified medical practitioner. In respect of legal, financial or other matters covered by this information, you should also consider seeking specific professional advice about your personal circumstances.

While we try to ensure that this information is accurate, we do not accept any liability arising from its use. Please refer to our website for our full terms and conditions.

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 support us, visit mariecurie.org.uk/get-involved or use the QR code.

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