

Fatigue



**VERSUS
ARTHRITIS**

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We're the 10 million people living with arthritis. We're the carers, researchers, health professionals, friends and parents all united in our ambition to ensure that one day, no one will have to live with the pain, fatigue and isolation that arthritis causes.

We understand that every day is different. We know that what works for one person may not help someone else. Our information is a collaboration of experiences, research and facts. We aim to give you everything you need to know about your condition, the treatments available and the many options you can try, so you can make the best and most informed choices for your lifestyle.

We're always happy to hear from you whether it's with feedback on our information, to share your story, or just to find out more about the work of Versus Arthritis. Contact us at content@versusarthritis.org

Words shown in **bold** are explained in the glossary on p.24.

What is fatigue?

Fatigue is an extreme, sometimes overwhelming, physical and mental tiredness, that doesn't significantly improve with rest or sleep.

It's a common problem associated with arthritis and can make other symptoms, such as pain and joint stiffness feel more severe and limiting.

It can affect your motivation and your ability to concentrate, this is sometimes described as having brain fog. Some people find it affects their emotional wellbeing making them feel irritable or depressed.

People with fatigue often say it's similar to having the flu, with symptoms such as:

- their body and limbs feeling heavy and difficult to move
- exhaustion
- feeling their energy has drained away.

Fatigue is unpredictable. It can start suddenly at any time of the day. Some days you may feel exhausted from the moment you wake up, even if you think you slept well.

It can last an hour, a day, or several days. Some people may find it lasts longer.

It can make you feel as though you haven't the strength or energy to achieve even simple everyday tasks.

People with fatigue often feel they have to miss out on things they enjoy doing, to save energy for jobs or tasks. However, missing out on the things that lift your mood can make fatigue worse.

Fatigue is more extreme than simple tiredness. However, there are ways you can manage it and reduce its impact on your life.

People with fatigue often feel they must save their energy for tasks they have to do but, by missing out on things you enjoy, you can make fatigue worse.



What causes fatigue?

Fatigue is your body's reaction to a build-up of stressful events, experiences, health issues or feelings.

Usually there isn't a single reason for fatigue, it tends to be caused by a combination of factors.

The causes can be different for everyone. It could be the result of:

- inflammation, which can cause swelling, redness, heat and pain as the body tries to heal an infection or injury by sending more blood and fluid to the area
- anaemia (an-ee-me-a), where a lack of red blood cells, which deliver oxygen around your body, can lead to weaker muscles and lower energy levels. It can be caused by iron deficiency. Anaemia can be linked to conditions such as **rheumatoid arthritis**, **lupus** and **ankylosing spondylitis**. It can be a side effect of some arthritis treatments.
- some treatments, such as some drugs to stop seizures, anti-depressants and anxiety medications, opioid-based painkillers, some muscle relaxants, antibiotics, and long-term use of oral steroids. Drug treatments can affect people in different ways, talk to your doctor or pharmacist if you have any concerns.
- long-term conditions, such as **inflammatory arthritis** or autoimmune conditions
- pain
- muscle weakness caused by pain and inactivity
- overdoing it with boom and bust behaviour. This is when you carry on with your tasks, ignoring your pain or tiredness, until you physically and mentally cannot continue.
- poor quality sleep
- stress and anxiety
- missing meals, poor diet or not drinking enough water and other healthy non-alcoholic drinks means your body has less energy to rely on.

Fatigue and arthritis

Arthritis is commonly associated with pain and stiffness. It can affect your general health, sleep, weight, emotional wellbeing and the amount of activity you feel able to do.

Many people with arthritis say fatigue is one of their biggest challenges.

Fatigue can be linked to many types of arthritis and related conditions. It's commonly a symptom of autoimmune conditions, such as rheumatoid arthritis, **reactive arthritis** and lupus. In autoimmune conditions the immune system mistakenly attacks the body's own healthy tissues.

It's also strongly linked to conditions that can cause long-term pain, such as **fibromyalgia**, **polymyalgia rheumatica** and **complex regional pain syndrome**.

People with **osteoarthritis** have also reported having fatigue.

Fatigue can feel overwhelming but there are ways to manage it and lessen its impact on your life.

You can find more information about your condition by visiting our website: www.versusarthritis.org



Alternatively, call our free helpline on 0800 5200 520 to order a booklet about your condition, or ask for one at your GP surgery.



Talking to your doctor about fatigue

There are several things that can reduce the impact of fatigue. Firstly, it helps if you can work out what could be causing it.

There aren't any specific tests for fatigue. However, you can help your doctor's diagnosis by writing down how you feel, what could be causing it and how it's affecting your life. They may also be able to provide you with a self-assessment questionnaire to fill out.

Depending on your symptoms your doctor may recommend you have blood tests to check your fatigue hasn't been caused by another condition. If it has been, treating this condition may improve your fatigue.

There aren't any specific drug treatments for fatigue. However, your doctor, physiotherapist, occupational therapist or rheumatology team, should be able to help you recognise the signs and learn to manage them

How can I help myself?

There are a number of things you can do to help manage your fatigue.

Planning your time wisely to spread your energy over the course of a day or week can help. It's also important to factor some gentle exercise into your day and to have a healthy diet.

There's a strong link between getting enough good quality sleep and fatigue. And there are several positive steps you can take to improve your chances of sleeping well.

Stress and worry can make your fatigue feel worse, so it's a good idea to spot anything that is causing you stress and try to deal with them in good time.

When you have fatigue, it's easy to ignore what you've achieved and worry about the things you haven't. But, given how challenging daily life can be, everything you can do counts.

The four Ps

The four Ps are problem solving, planning, prioritising and pacing. The aim is to think of the four Ps at the beginning of each day or week to help you manage your energy levels. It can take a while to master this way of thinking, but it's worth being patient with it because it can make a difference.

Problem solving

It's easier to manage your energy if you can work out what problems might be adding to your fatigue and thinking of ways around them.

For example, if cleaning your house is becoming an overwhelming task and using up so much energy that you find it difficult to do anything else, how could you make it easier?

Would it help to get a cleaner? Sometimes we all have to pay someone to help get a job done. If it means you have more energy to do other things, such as paid work, the benefits should be greater than the cost.

If you find it tough doing a weekly shop at a supermarket, could you do online shopping?

Often small changes can alter the amount of energy you use and the way you feel about yourself.

Planning

Try to plan the things you want to achieve in your day or week. If you have a big job that will need a lot of energy, try breaking it into achievable tasks that can be spread through your day or week. Plan to do bigger tasks at a time of the day when you tend to have more energy. Plan lighter activities and rest breaks around them.

It's also important to plan activities you enjoy into your day, it's not just about getting tasks and chores done. Taking part in activities you enjoy can improve your mood and energy levels.

Try to stick to your daily plan, but don't beat yourself up if you can't do everything. Your healthcare team should be able to help you set and review realistic goals.

Prioritising

While you're planning your day or week put your activities into an order of importance. Ask yourself:

- Does this need to be done today?
- Does it need to be done at all?
- Do I have to do it, or can I ask someone else?
- Can I get someone to help me with parts of the task?

Pacing

Pacing is about not using up all your energy in one go. We've already talked about breaking activities into smaller tasks, particularly ones that you'll need a lot of energy for. You could then spread out these pieces of activity over the course of a day, a week or longer.

For example, instead of doing all your cleaning in one go and then feeling wiped out later that day and the next day, could you spread it out over a week or a fortnight, and do it room by room? This could make it more manageable and less overwhelming.

As you get better at using the four Ps to manage your time you should see a noticeable difference in your energy levels and the amount you feel you've achieved.

Lists and charts

A good way to measure how you're using your energy and the way it makes you feel is to use a list or chart.

Try listing the following:

- the time you wake up
- how you've slept
- the main activities you do throughout a day and the time you do them
- how you feel after each activity
- when you take time to rest and recover
- when you go to bed
- how you feel by bedtime.

This list or chart should help you spot trends and habits that affect the way you feel. For example, you may see a link between the way you're feeling, the activity you're doing and the time of day. You can then try to change the way you're doing things to save energy.

Try using a chart or list over a couple of weeks to see if you can change the way you feel by adjusting the way you do things.

See the back of this booklet for a chart that might help you.



Increase your physical activity

Adding some gentle exercises to your day can increase the amount of energy you have.

Staying active increases your fitness levels and strengthens your muscles. Weak muscles use more energy, so doing too little can be as damaging as doing too much.

Exercise also increases your circulation and improves the health of vital organs, such as your heart and lungs, which can also give you more energy.

It's important to give yourself time to recover after exercise by taking a break before you move onto your next activity.

When you start exercising

Introducing more physical activity to your day may be tiring at first. Don't overdo it, start your activity slowly, perhaps just add a 5–10 minute walk or some gentle stretching exercises to begin with.

If you're in pain you can take painkillers before you exercise.

Gradually build up the amount of activity you do. For example, when you're ready, walk for 5 more minutes or add some strengthening exercises to your routine.

Generally, the best way to build up your fitness levels is to do a little exercise as often as you can. Stick with it because as you get fitter you'll start to feel better, stronger and more energetic.

You could try using a step counter such as a fitness tracker, a pedometer, or a mobile phone app. When you're ready and depending on how you're feeling, you could try to beat your previous records.

You should aim to exercise every day. But be aware some days will be easier than others.

Each day, before you start, think about how you're feeling and make allowances if need be. Vary the types of exercises you're doing and the intensity according to how you feel.

Fatigue information booklet

Don't put yourself under too much pressure. Sometimes you will feel more fatigued, so try to do lighter exercise, such as light stretching and gentle walking, on those days. Take advantage of the times you feel stronger and more energised to do more strenuous, vigorous activities.

A physiotherapist is a specialist trained to help people with long-term health conditions or injuries to regain their independence through movement, exercise, manual therapy, education and advice. They can advise you on specific exercises and refer you to a gym or a healthy walks programme in your area.

Trained fitness instructors often work closely with physiotherapists and health centres to help people with conditions find exercise routines that could improve their strength and energy.

You can also gradually increase your daily activities, for example housework and gardening. An occupational therapist can help you work out a realistic way to achieve your goals. They are specialists trained to help you adapt to your condition. They can show you ways to do everyday tasks, either by changing how you do them or by using specially designed equipment.

See our information and tips about exercise in the managing your symptoms section of our website at www.versusarthritis.org



You can also find more information about physiotherapy and arthritis in our website's treatment pages, which are in the about arthritis section.

You can speak to one of our helpline advisors on 0800 5200 520 for more advice and to order the free Versus Arthritis booklets Keep moving; Physiotherapy and arthritis.



Get a good night's sleep

It's important to try to get a good night's rest because poor sleep patterns can cause fatigue or make it worse.

If you're having trouble sleeping, or you regularly wake up feeling unrefreshed, it would probably help to look at ways you might be able to sleep better. Healthcare professionals talk about a principle called sleep hygiene, which covers things you can do to improve your chances of getting a good night's sleep.

Too much sleep can also cause fatigue. Thinking about what a good night's sleep means to you, can help. Your activity charts can tell you a lot about how you're sleeping.



Fatigue information booklet

For more advice on what causes sleep problems and how to improve the quality of sleep you're getting, take a look at our information about sleep on our website www.versusarthritis.org/sleep



You can also find helpful tips in our free booklets *Everyday living and arthritis*; *Sleep and arthritis*; *Painkillers and NSAIDs*; *Steroid injections*. This information is also available online.



Talk about how you're feeling

Fatigue can make you feel low or depressed. Talking about how you feel can really help. Don't keep your feelings to yourself. Try to talk to a member of your healthcare team, members of a support group, your family or friends.

There are things that can help if you're feeling low. Your healthcare team may recommend a talking therapy, such as cognitive behaviour therapy – also known as CBT. You can do it as one-to-one or group sessions.

Talking therapies aim to help people change the way they see their condition and any negative feelings towards it. Sessions, led by trained therapists, can help people change the way they react to and feel about their condition by making positive changes to the way they think and behave.

NHS England has a dedicated programme called Improving Access to Psychological Therapies, known as IAPT. It aims to connect people with anxiety and depression to local talking therapy services. You can refer yourself to this service by visiting the NHS England website and searching for IAPT, or ask a health professional to refer you.

Health services in Scotland, Wales and Northern Ireland don't currently offer a self-referral service, but you can ask your doctor to refer you to a local NHS therapy service or group.

Joining a support group for people living with similar conditions can help you talk openly about your problems with people in similar situations. They may also be able to share tips on how to get around some of your problems.

Alternatively, you may benefit from a short course of medication, such as anti-depressants. Some of these treatments can improve your pain and sleep, as well as your mood.

For more information visit: www.nhs.uk/service-search/find-a-psychological-therapies-service/



Stress and anxiety

Increased stress and anxiety can cause fatigue. And fatigue can lead to increased feelings of stress and anxiety.

If there's something you're worried may become too overwhelming or stressful it's best to try to tackle it sooner, rather than later. Try to deal with it as positively as possible.

Think how you can change the situation without it making you too anxious. Is there someone you could turn to for help, support and advice?

It's easiest to open up to other people who have fatigue because you understand each other's difficulties, and you can support each other and share ideas for coping.

Try to find the easiest and best way to solve the problem. Breaking it down into smaller tasks or parts may make you feel better about it.

Your occupational therapist or a specialist nurse may be able to offer you some help.

It's important that you give yourself time to relax and unwind. Sometimes the distraction of something as simple as going for a walk, gardening, taking a bath or reading a book can help.

Relaxation techniques, such as mindfulness or meditation, can reduce your physical reaction to stress. Your doctor should be able to suggest some simple relaxation methods, or there are lots of books, CDs, websites and mobile apps available.

Join a support group

Talking about your condition to like-minded people can help a lot. Your healthcare team may be able to tell you about groups for people with conditions like yours.

There may be groups in your area that specialise in helping people with fatigue or conditions that cause fatigue.

Joining a support group is a great help for sharing problems and learning coping strategies. However, fatigue can be different for everybody, even people with the same condition. It often means different things to different people.



Helping people around you understand fatigue

Fatigue is a major symptom of many conditions, such as arthritis – often it's as much of a problem as pain and inflammation. But it's an invisible symptom and a lot of people avoid talking about it because they think their family, friends and colleagues won't understand.

It can be stressful if you think people around you don't understand how you're feeling. Even when you explain, some people may struggle to realise how fatigue affects you and that it stops you doing certain activities. This can be frustrating and tiring and can put a big strain on your relationships. Getting help, support and understanding from the people around you can make a huge difference.

Good communication and explaining clearly and calmly how fatigue affects you is important to help others understand.

It's ok to say that you need help with tasks around the home.

Learning to say you can't do something or go somewhere because of the way it will affect you can help. It may also reassure people that sometimes you just don't feel up to socialising and it's no reflection on their company.

If people ask for your help with something, remember it's ok to say no. It's ok to put yourself first.

If you find it difficult to talk about your fatigue, you could ask people to read this information.

At work

If you feel fatigue stops you doing your job properly there may be things you can change that would make it easier.

Travelling to and from work can add to your levels of fatigue. Is there anything you could do to make it less tiring? Could you work from home for at least some of the week, or start your shift at a different



Fatigue information booklet

time on some days? Is there another way you could get to work that is less strenuous? Could you car-share with someone you work with?

An occupational therapist can advise you on ways around your fatigue. They can help you work out realistic goals. They can also suggest ways to save energy and keep your stress levels down. They may be able to recommend aids or adaptations that would help you do your job.

Talking to your employer about your fatigue and explaining how it affects your work could help. If there are jobs you're struggling with, your line manager may be able to help you come up with a solution.

They may offer an occupational therapy service, or you could ask your doctor to refer you. Alternatively, you could see one privately, though you would have to pay for it.

You shouldn't be worried about talking to your employer about your fatigue. You have rights that are protected under employment law.

Your local Jobcentre Plus can put you in touch with Disability Employment Advisors. They can arrange work assessments, advise you on the best ways to work around your fatigue and tell you about any aids and adaptations that might help you do your job.

See the work information on our web pages
www.versusarthritis.org/work



You can find out more about occupational therapy by
visiting the treatments section of our website.

You can find contact details for your local Jobcentre Plus
in a phone book or at www.gov.uk/contact-jobcentre-plus

Eat a healthy diet

Eating a well-balanced diet will help to provide all the nutrients you need for general well-being and energy. It's important that you eat regular balanced meals to keep your energy levels up.

See our information on healthy eating in the
managing your symptoms pages of our website
www.versusarthritis.org



You can order our free Diet and arthritis booklet
by talking to a Versus Arthritis helpline advisor on
0800 5200 520.



Research and new developments

Versus Arthritis-funded research has found talking therapies can help reduce the impact fatigue has on people with arthritis. Our researchers are currently testing whether these therapies can be provided as a treatment by rheumatology teams.

Versus Arthritis is also funding a review of the interventions that can be offered to help combat fatigue in people with rheumatoid arthritis. Most new drug treatments for inflammation in arthritis are now also tested to see if they reduce fatigue.

Glossary

Ankylosing spondylitis

Ankylosing spondylitis (an-kee-lo-sing spon-dee-lye-tis) is a long-term condition that affects your spine. It can also cause inflammation in large joints.

Complex regional pain syndrome (CRPS)

Complex regional pain syndrome (CRPS) is a condition that causes severe pain which won't go away. It usually affects just one arm or leg and often follows an earlier injury to the limb.

Fibromyalgia

Fibromyalgia (fye-bro-my-al-juh) is a long-term condition which causes widespread pain and fatigue throughout the body. It doesn't stem from inflammation in any specific body part. It's thought to be caused by the brain and spine misunderstanding pain signals from other parts of the body.

Inflammatory arthritis

Inflammatory arthritis refers to a group of conditions that cause inflammation, usually of the synovium, which is the lining of the joint. Types of inflammatory arthritis include rheumatoid arthritis, psoriatic arthritis and ankylosing spondylitis.

Lupus

Lupus, also known as systemic lupus erythematosus (SLE), is a condition where the body's immune system attacks healthy cells instead of infections. Lupus can affect the skin, hair and joints, and can sometimes affect the internal organs, such as the heart or kidneys.

Osteoarthritis

Osteoarthritis (os-tee-o-arth-rye-tus) is the most common form of arthritis. It causes damage to the surfaces of a joint which can lead to pain, swelling and stiffness. Osteoarthritis mainly affects the hands, knees and hips.

Polymyalgia rheumatica

Polymyalgia rheumatica (pol-ee-my-al-juh roo-mat-i-kah) (PMR) is a condition that causes pain, stiffness and inflammation around the shoulders, neck and hips.

Reactive arthritis

Reactive arthritis is a relatively short-lived condition causing painful joint swelling. It develops shortly after an infection. It usually clears up after a few months but can last longer.

Rheumatoid arthritis

Rheumatoid arthritis (room-a-toyd arth-rye-tus) is a long-term condition that can cause pain, swelling and stiffness in your joints.

Thank you!

A team of people helped us create this booklet. We would like to thank Joseph Loades and Emma Henry for helping us review this booklet.

We would also like to give a special thank you to the people who shared their opinions and thoughts on the booklet. Your contributions make sure the information we provide is relevant and suitable for everyone.

Where can I find out more?

If you've found this information useful, you might be interested in other titles from our range. You can download all of our booklets from our website www.versusarthritis.org or order them by contacting our Helpline. If you wish to order by post, our address can be found on the back of this booklet.

Bulk orders

For bulk orders, please contact our warehouse, APS, directly to place an order:

Phone: 0800 515 209

Email: info@versusarthritis.org

Tell us what you think

All of our information is created with you in mind. And we want to know if we are getting it right. If you have any thoughts or suggestions on how we could improve our information, we would love to hear from you.

Please send your views to bookletfeedback@versusarthritis.org or write to us at: **Versus Arthritis, Copeman House, St Mary's Court, St Mary's Gate, Chesterfield, Derbyshire S41 7TD.**

Talk to us

Helpline

You don't need to face arthritis alone. Our advisors aim to bring all of the information and advice about arthritis into one place to provide tailored support for you.

Helpline: 0800 5200 520

Email: helpline@versusarthritis.org

Our offices

We have offices in each country of the UK. Please get in touch to find out what services and support we offer in your area:

England

Tel: 0300 790 0400

Email: enquiries@versusarthritis.org

Scotland

Tel: 0141 954 7776

Email: scotland@versusarthritis.org

Northern Ireland

Tel: 028 9078 2940

Email: nireland@versusarthritis.org

Wales

Tel: 0800 756 3970

Email: cymru@versusarthritis.org

Sample activity chart

Try planning the next few weeks and review your progress as you go.

Date	Midnight to midday (morning)											Midday to midnight (afternoon/evening)												
	12	1	2	3	4	5	6	7	8	9	10	11	12	1	2	3	4	5	6	7	8	9	10	11
__/__/__																								
Monday																								
Tuesday																								
Wednesday																								
Thursday																								
Friday																								
Saturday																								
Sunday																								

Key:

- High-energy activity (physically, mentally or emotionally demanding tasks)
- Low-energy activity (something which doesn't use a lot of energy)

- Rest time
- Sleep

- Fatigue (when you've had to stop what you were doing, sit down or go to bed to rest)

Fatigue

Fatigue is a very common problem, particularly if you have arthritis or another long-term condition. It can make all your other symptoms feel far worse. But there are ways to manage fatigue and lessen its impact on your life.

In this guide we'll explain what fatigue is, what causes it and how you can learn to manage it.

For information please visit our website:

versusarthritis.org

0300 790 0400

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