

Fatigue and brain tumours

Fatigue is often described as a persistent feeling of being tired, weak, worn out, slow or heavy. It is a common symptom for people with all types and grades of brain tumour.

Cancer-related fatigue is often talked about, but less acknowledged is that people with low grade ('benign'/'non-cancerous') brain tumours also often experience fatigue. Many people say that it is one of the most disruptive side-effects they experience.

This fact sheet helps you understand why you may have less energy now than you did before you had a brain tumour. It also offers some practical suggestions for coping with the emotional and physical effects of fatigue.

In this fact sheet:

- What is tumour-related fatigue?
- What are the symptoms of fatigue?
- Why am I getting fatigued? (low and high grade tumours)
- How can I cope with fatigue?
- Answers to some commonly asked questions that you may have about fatigue

What is tumour-related fatigue?

Not everyone with a brain tumour will experience fatigue and those that do will experience it differently. For some, it will be relatively mild; for others it can be very disruptive to their quality and way of life.

Tumour-related fatigue (from all grades of tumour) can be an endless, draining sense of extreme, whole body weariness. It can vary in intensity from day to day or throughout the day.

The key difference between this and the fatigue that someone who does not have a tumour might experience, is that tumour-related fatigue is not usually relieved, or improved, by resting or by sleep.

Feeling like this can, understandably, have a negative impact on how you feel emotionally. This, in turn, can affect your sleeping patterns, making you more tired, more fatigued.

Fatigue cannot be seen and it can vary from person to person. As a result, it is often misunderstood. It can be difficult for other people to really understand how it feels.

Friends and family, and even patients themselves, therefore, sometimes see fatigue as 'laziness' or wonder if the patient is exaggerating symptoms. This is obviously not the case, but it can cause more stress, adding to the fatigue.

Fatigue can therefore profoundly affect your personal, social and working life, leading to difficulties in relationships, social isolation and loss or reduction in employment. This in turn can cause financial difficulties, extra stress and more fatigue.

(Many carers also experience fatigue. This can be due to extra worry and stress, extra physical activity involved in caring and possibly lack of sleep. For more information, see our Carers - looking after yourself fact sheet.)

I have a low grade ('non-cancerous') tumour, why am I getting fatigued?

People with low grade ('non-cancerous'/'benign') brain tumours may experience fatigue for several reasons:

- The tumour will be having an 'impact' on the brain, which could be making routine tasks more difficult. The greater concentration required for these tasks is in itself tiring.
- If you are having treatments, such as chemotherapy, radiotherapy, anti-epileptic drugs or steroids – one of the side-effects can be fatigue.
- If you have seizures, which are more common in low grade tumours, these can cause fatigue.
- The stress and anxiety caused by the diagnosis and the uncertainty, particularly if you are on 'watch and wait' is also fatigue-causing. (See the *Watch and wait* fact sheet for more information.)

What are the symptoms of fatigue?

People can experience fatigue in different ways, and you are unlikely to experience all of these, but common symptoms include:

- A lack of energy (feeling like you just want to stay in bed all day)
- Over-sleeping, or sometimes difficulty sleeping
- Aches in your muscles (for example, when climbing stairs or walking even short distances)
- Feeling exhausted after small tasks, such as taking a shower or making your bed
- Difficulty concentrating (for example, on watching television or chatting to a friend)
- Loss of interest in the things you usually enjoy

- Finding it difficult to make decisions or think clearly
- Irritability
- Negative feelings about yourself and others
- Feeling anxious or depressed

Why am I getting fatigued?

The exact cause of fatigue is not known, but it is thought that there are several things that could contribute to it, including:

The tumour itself

The development, growth and/or progression of a tumour (of any grade) and the body's response to it, involves the destruction of cells and the repairing of tissue - both of which require a lot of energy. As a result, your body is working harder, and some of the energy that you would normally use on everyday living, is 'diverted' to fight the tumour.

Tumour-related fatigue, therefore, can begin at, or even before, diagnosis.

Your treatment

Surgery

Fatigue after any major surgery is very common, not just surgery on the brain. It is due to a combination of factors, including the anaesthesia and sedative drugs given. The healing process also requires a lot of the body's energy.

This sort of fatigue usually lasts for a few days to several months. However, when it follows surgery on the brain, it can last for longer than a year, as the 'insult' on the brain caused by surgery can take some time to heal. Also removal of brain tissue can lead to negative effects on brain functions, such as concentration, problem-solving, communication, and can cause weakness or co-ordination difficulties. It can be tiring compensating for these surgery side-effects.

For more information, please see the *Cognition and brain tumours* and the *Neurosurgery for brain tumours (adults)* fact sheets.

Radiotherapy

It is very common to feel tired during your treatment and, as the weeks of radiotherapy go on, you may feel increasingly more so. This may be because your body is using its resources to repair any damage to healthy cells caused by the radiotherapy.

It may also be because of all the journeys you are making to and from the hospital.

Unfortunately, the feeling of tiredness does not immediately stop once the treatment stops and may continue for a number of weeks afterwards.

Some people can get a rare side-effect where, a few weeks after treatment has finished, their tiredness becomes severe. This is called 'somnolence syndrome'. However, it gets better on its own over a few weeks without any treatment.

Let yourself rest or nap when you need to without feeling that you must fight the tiredness. Some people have found a short, gentle walk from time to time helpful.

For more information, please see the *Radiotherapy* fact sheet.

Chemotherapy

Many people experience fatigue following chemotherapy. This can be because chemotherapy can reduce the production of your red blood cells - a condition called anaemia. The red blood cells contain a protein called haemoglobin that carries oxygen around your body allowing your muscles to work. A reduction in haemoglobin levels can therefore leave you feeling very tired.

As a result, in between cycles of chemotherapy, many people have periods where the tiredness gets gradually worse, but then improves to its lowest level just before the next round of chemotherapy.

Your doctor can check for anaemia with a blood test and advise on treatment if appropriate.

Some research has also shown that the body requires energy to repair itself following treatment and that the immune system needs to adapt. This can drain energy as the body re-directs its resources towards healing.

For more information, please see our *Chemotherapy* fact sheet.

Medication

Some medications can increase the risk of fatigue. These include painkillers, sleeping tablets and anti-depressants. Steroids may cause daytime fatigue by keeping you awake at night, or some people find they become fatigued when they are withdrawn from steroids. For this reason it is best to withdraw gradually.

Speak to your doctor if you are experiencing fatigue and feel it may be the result of your medication. They may be able to offer you an alternative or change the dose to make it easier for you to cope.

Cognitive effects of brain tumours

Many people diagnosed with a brain tumour will have some form of 'cognitive impairment', due to the presence of the tumour and the pressure it causes on the brain. Cognitive impairment can include difficulty in concentrating, remembering things, understanding things or solving problems. Trying to overcome these can be extremely tiring and contribute to fatigue.

For more information, please see our *Cognition and brain tumours* fact sheet.

In turn, fatigue is well-known to cause cognitive impairment, particularly with memory, attention/concentration and planning and organising, as it can deplete the energy required for these functions. As such, a vicious circle is created.

Seizures

Around 60% of people with a brain tumour will experience a seizure at least once. You are more likely to have seizures if you have a slow growing, low grade tumour.

There are many different types of seizures. Common symptoms after any seizure include feeling tired or exhausted. You may sleep for minutes or hours.

As with all medications, anti-epileptic drugs (AEDs) can have side-effects, including making you feel fatigued. These side-effects will depend on which drug you have and how you react to the drug.

Having seizures and being diagnosed with epilepsy on top of the diagnosis of a brain tumour can also be overwhelming. You may feel frightened, worried, anxious, depressed, angry - all of which can add to your fatigue.

For more information about seizure, please see the *Epilepsy (seizures) and brain tumours* fact sheet.

Stress, anxiety and depression

Living with a brain tumour of any grade can cause a huge amount of stress and anxiety, which in turn takes up a lot of energy and can affect quality of sleep, leading to fatigue. Some people living with a brain tumour experience depression, which can also leave you feeling physically and mentally exhausted. For more information, see the *Depression and brain tumours* fact sheet.

Speak to your health team if you feel you are depressed - they may be able to prescribe medication or other treatments that can help.

Diet

The side-effects of brain tumour treatments can make you too tired to cook or eat. They may also make you feel nauseous or cause you to vomit. They can give you constipation or affect your sense of smell or taste. This can make it difficult to eat the necessary amount or variety of food that would aid your body in its recovery.

Eating less means you are taking in fewer calories. If the calories you are taking in are less than those you burn it can leave you feeling very tired.

Dehydration

Dehydration happens when you don't have enough fluids in your body. This can happen if you are being sick (vomiting) and/or not drinking or eating enough. As well as losing fluids, dehydration can cause changes in salts and minerals in the

body called electrolytes. Electrolytes, such as sodium chloride, are important in controlling the fluid balance of the body.

Dehydration can lead to tiredness. It can also lead to feeling or being sick (vomiting). Being sick leads to a further loss of fluids and electrolytes, making you feel more tired.

If you are concerned that you are dehydrated, as well as drinking more water, seek medical advice from your doctor, as you may need help to restore your electrolyte balance.

Pain

Some people living with a brain tumour experience pain on a daily basis e.g. headaches. Dealing with it day to day can wear you down, causing fatigue. Being fatigued, in turn, can make it more difficult to cope with and manage pain.

As well as using pain killers, some people find that techniques such as relaxation and acupuncture help to alleviate pain and therefore help with fatigue. Let your medical team know if you are having acupuncture.

Cytokines

Cytokines are proteins that are made by the cells involved in the immune system, and are produced in response to injury or infection. There is evidence that the levels of cytokines are higher in some tumour patients, possibly due to the body fighting the tumour.

It is thought that the higher than normal levels of cytokines could cause fatigue by affecting hormones and chemicals that nerve cells use to communicate.

More research is needed to find out exactly how these increased levels cause fatigue.

Is there a cure for tumour-related fatigue?

While there is not a cure for fatigue, it can be helpful to remember that for many people fatigue usually improves after treatment has ended (usually within six months to one year).

However, within that time it can be debilitating and some people do continue to experience it for longer.

Up to 80% of people think there is nothing that can be done for this type of fatigue. As a result, they don't even mention it to their doctors. However, there are ways that can help to ease or cope with it.

So if you are experiencing fatigue that is affecting your quality of life, try some of the suggestions below and also speak to your health team. They can help with elements that are treatable e.g. pain, anxiety, depression, anaemia, or refer you to other specialists that can help e.g. counsellors or support groups.

How can I cope with fatigue?

Fatigue can form a vicious cycle with the side-effects of brain tumours and their treatments. As described, the tumour and its treatment can make you tired or fatigued. Fatigue can increase side-effects, such as cognitive impairment or depression, which, in turn, can make you more tired, and so the cycle continues.

The aim is to try and work out what daily patterns or habits tend to make you fatigued and find a way to break the cycle.

Suggestions for helping people with fatigue can be broken down initially into three P's - **prioritising, planning, pacing** - with other factors also playing a role in helping you to cope with fatigue.

Prioritising

Write a list of activities that you do regularly.

Assign priorities to them with one being the most important to you. For example, walking the dog may be a one; seeing friends, a two; and ironing, a six.

As it can be quite tricky to do this, you could maybe split the activities into four categories:

- things I have to do
- things I want to do

- things someone else can do
- things that don't need doing at all (or at least don't need doing so often).

Planning

Keep a fatigue diary

Keeping a diary of your activities and when you feel fatigued might help you to identify possible triggers.

It may also help you to see any patterns in your energy levels, for example, when they tend to be at their highest.

You could colour code your activities - red for high intensity (e.g. exercise, shopping, work); orange for moderate intensity (e.g. household tasks, meeting friends); and green for lower intensity tasks (e.g. rest, relaxation, sleep, sitting quietly). It is important that you have a balance between rest and activity.

You can use this information along with your list of priorities to help plan your day.

Set yourself realistic goals

Having goals to work towards gives us a sense of purpose, and achieving them makes us feel good, but don't be too ambitious.

If doing exercises, keep a record of the number of repetitions you complete, so you can see any improvements.

Make a realistic, achievable action plan, carry it out, review it, and then **reward yourself** for your achievements.

Pacing

Break down your tasks into smaller, manageable chunks

You could use the categories described in the prioritising section to break one large or more difficult task into manageable chunks.

Take frequent breaks

Plan short rest breaks throughout the day, but try not to sleep during these rests as this could affect your sleeping pattern at night leading to increased fatigue.

As a guide, rest for 10 minutes in every hour that you are doing an activity. Also change activities roughly every hour.

Stop if you are getting tired

Don't feel you have to stick to your plan. If you find you are getting tired, stop. You can review your plan later and amend it.

Conserve energy and keep 20-30% energy in reserve

As you may have less energy now than you used to, think about how you can 'spend' or 'save' this energy wisely.

This could include things such as shopping online, or asking others to help you with some things that you used to do alone so that you save your energy for the things that are important to you.

Other factors

Other suggestions that can help you cope with fatigue include:

Treat specific causes

This can include treating anaemia, depression and pain. You may also be taking medication that is contributing to your feelings of tiredness. Speak to your medical team about swapping to different medications or changes in dosage.

Stay physically active or take some structured exercise

Exercise, even if only for five minutes. Gentle to moderate intensity exercise, such as walking, gardening or swimming, is believed to give individuals living with cancer or lower grade tumours, more energy, reduced pain, better sleep quality and an improved sense of well-being. It can also help to stimulate appetite.

Inactivity can lead to breathlessness and muscle weakness, which adds to feelings of fatigue.

Try to find a type and level of exercise you can manage and would enjoy doing most days of the week. Your local leisure centre may have suitable classes e.g. yoga, where you can exercise in a gentle way under supervision, if you prefer.

After the exercise, you should feel energised, not wiped out.

Keep your mind active

Puzzles, such as jigsaws or Sudoku, can help to stimulate your mind. Some people say that activities such as gardening or arts and crafts help them to feel mentally refreshed. In fact, research suggests that a key element of physical fatigue may be cognitive fatigue, so getting back to some normality and engaging in interests, activities and hobbies can be helpful.

Have a regular sleep pattern

It is important to get a balance of activity, rest and sleep. Try to have a regular sleep pattern and avoid sleeping during the day, which can leave you feeling more groggy.

Other things that help aid restful sleep include avoiding caffeine and alcohol close to bed time, and having your bedroom at a comfortable temperature.

It is also advisable to avoid using back-lit devices and screens, such as many Smart phones, laptops, some Kindles or TVs, within 1-2 hours of going to bed. These devices give out a large amount of blue light. This type of light has been shown to delay the release of a hormone called melatonin, which your body uses to help you fall asleep.

If, after 30 minutes, you find that you are unable to sleep, it can help to get up and go to another room to read or listen to music until you feel sleepy. Then go back and repeat your routine of getting ready for bed again.

Eat like a marathon runner!

Pasta, fruit and whole-grain breads are full of complex carbohydrates that provide long-term energy. Eating little and often will help keep your energy levels stable,

particularly if you combine these complex carbohydrates with vegetables, dairy and a small amount of protein.

If you have the energy to cook, try to use fresh ingredients. Over-processed or refined foods have less nutritional value and so provide less or only short-term energy. Similarly, take-away food tends to be high in calories, fat and salt and low in energy-boosting properties, so are best only as a last resort.

Prepare your food sitting down and, if possible, make large amounts - these can be frozen for future meals. Ask people to help you in the kitchen. Alternatively, use frozen vegetables or pre-cut foods to make it easier to eat healthily.

Finally, using snacks, ready-made meals (select these carefully) and including puddings could reduce the burden of cooking if you feel tired. You could also ask friends or family members to cook dishes in bulk and freeze portions so you can have them ready to defrost whenever you need to.

For more information, see the *Diet and brain tumours* fact sheet.

Manage stress and anxiety

Stress and anxiety use a large amount of energy. If you can recognise your triggers to stress and anxiety, as well as your body's response to them, it can help you to find ways to cope with them.

Relaxation techniques, such as mindfulness or breathing exercises, can be used when you recognise a trigger or start to feel your body respond in a negative way. Other people have found relaxation aids, such as colouring books, gentle music DVDs, herbal pillows, to be helpful. Alternatively, relaxation groups, or exercises, such as yoga or tai chi,

Counselling can also help with feelings of stress, anxiety and depression.

Your GP will be able to provide further information and should be able to refer you to a counsellor, if appropriate.

Find reputable information and talk about it

Gaining support in its various formats, including accessing information about brain tumours and talking about your worries, has been shown, in some research studies, to help reduce fatigue.

Information about all aspects of living with a brain tumour can be found on The Brain Tumour Charity's website.

thebraintumourcharity.org/understanding-brain-tumours/

(The Brain Tumour Charity has been certified by The Information Standard (an accreditation scheme run by NHS England), as a provider of high quality health and social care information. Look for the quality mark - a quick and easy way to identify reliable and trustworthy sources of information.)



How can I explain my fatigue to others?

There are many analogies about conserving energy that you may find useful to apply to your own situation when trying to explain to others how you feel. They include:

- A rechargeable battery, which runs down more quickly than before you were ill.
- An A4-sized envelope. Before you had a brain tumour, you packed all your activities into the envelope and it closed easily. Now you only have an A5-sized envelope, so you can not fit in all of the activities that you used to.
- A car with a broken petrol gauge. You know there is 'fuel' in there, but you don't know how much is left, so you need to treat it more cautiously and think about how you could fill it up.

Resources you may find helpful

While The Brain Tumour Charity cannot recommend any specific resources, you may find the books listed below helpful in understanding and coping with your fatigue, whether you have a low or high grade tumour:

Coping with fatigue

Macmillan Cancer Support

You can order it online for free at: bit.ly/MacmillanCopingWithFatigue

or by calling **020 7840 7840**

Handbook of cancer-related fatigue

Dr Roberto Patarca-Montero

bit.ly/CancerRelatedFatigueHandbook

What if I have further questions?

If you require further information, any clarification of information, or wish to discuss any concerns, please contact our Support & Information Team:

- **Call: 0808 800 0004**
(Free from landlines and most mobiles: 3, O2, EE, Virgin and Vodafone)
- **Email: support@thebraintumourcharity.org**
- **Join our closed Facebook groups:**

bit.ly/facebooksupportgroup

bit.ly/carersupportgroup

About us

The Brain Tumour Charity makes every effort to ensure that we provide accurate, up-to-date and unbiased facts about brain tumours. We hope that these will add to the medical advice you have already been given. Please do continue to talk to your health team if you are worried about any medical issues.

The Brain Tumour Charity is at the forefront of the fight to defeat brain tumours and is the only national charity making a difference every day to the lives of people with a brain tumour and their families. We fund pioneering research to increase survival, raise awareness of the symptoms and effects of brain tumours and provide support for everyone affected to improve quality of life.

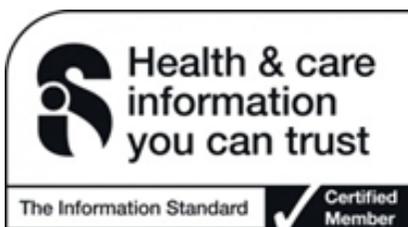
We rely 100% on charitable donations to fund our vital work. If you would like to make a donation, or want to find out about other ways to support us including fundraising, leaving a gift in your will or giving in memory, please visit us at thebraintumourcharity.org, call us on **01252 749990** or email fundraising@thebraintumourcharity.org

About this fact sheet

This fact sheet has been written and edited by The Brain Tumour Charity's Support & Information Team. The accuracy of information has been verified by a leading experts in the field. Our fact sheets have been produced with the assistance of patient and carer representatives and up-to-date, reliable sources of evidence. If you would like a list of references for any of the fact sheets, or would like more information about how we produce them, please contact us.

Fatigue

Your notes



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