

Fatigue and brain tumours

Living with a brain tumour



In a survey of people with a brain tumour, 3 in 5 people reported fatigue.

Of these people, 40% said they were severely affected.

Fatigue can affect people with low grade, as well as people with high grade brain tumours.



CARE CAN'T WAIT

If you'd like to talk to someone about how you're feeling, or would like to find out where you can get further support (including details of support groups), you can contact The Brain Tumour Charity's Information and Support Team:

Phone: **0808 800 0004**

(free from landlines and most mobiles)

Email: support@thebraintumourcharity.org

Live chat: thebraintumourcharity.org/live-chat

Website: thebraintumourcharity.org/getsupport

Closed Facebook groups:

thebraintumourcharity.org/facebook-support

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Introduction

Fatigue is often described as a persistent feeling of being tired, weak, worn out, slow or heavy.

It's a common symptom for people with all types and grades of brain tumour.

Many people say that it's one of the most disruptive side-effects they experience.

However, it's important to remember that while brain tumour-related fatigue can't be cured, it can be managed.

This fact sheet offers some practical suggestions for coping with the emotional and physical effects of fatigue.

It also helps you understand why you may have less energy now than you did before you had a brain tumour.

Is there a cure for tumour-related fatigue?

While there isn't a cure for fatigue, it's important to know that it can be managed.

It can also be helpful to remember that, for many people, fatigue improves after treatment has ended (usually within 6 months to 1 year).

Tumour-related fatigue can be debilitating and some people do continue to experience it for longer.

Up to 80% of people think there's 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 to help to ease or cope with it.

So if you're experiencing fatigue that's 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, including pain, anxiety, depression and anaemia. Or they can refer you to other specialists that can help, for example, 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 difficulties or depression. This 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 5 Ps - prioritising, planning, pacing, posture and permission - with other factors also playing a role in helping you to cope with fatigue.

Follow the 5 Ps for managing fatigue:

1. Prioritising
2. Planning
3. Pacing
4. Posture
5. Permission

Due to the cognitive effects of the tumour, some people may find some of the 5 Ps challenging. Get the support of family and friends. They can give you gentle reminders or prompts to help you manage your daily activities.

This makes it easier for you to have enough energy to do the things that give you pleasure and happiness.

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)
- **green** for lower intensity tasks
(e.g. rest, relaxation, sleep, sitting quietly).

It's important to have a balance of 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 how many 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 small, 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're doing an activity. And change activities every hour or so.

Stop if you're getting tired

Don't feel you have to stick to your plan. If you're 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.

Posture

- Have things at a level where you can easily reach them.
- Try to move regularly and not sit or stand in one position for too long.
- Sit down to complete a task - this saves a vast amount of energy.

Permission

Give yourself permission to say no, if you don't feel up to it or don't want to do something.

Delegate to others if/when you can.

Other suggestions

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

This may seem illogical, but try to exercise, even if only for 5 minutes.

Gentle to moderate intensity exercise, such as walking, gardening or swimming, is believed to give people living with high or low grade tumours:

- more energy
- reduced pain
- better sleep quality
- an improved sense of well-being
- stimulated appetite.

Inactivity, on the other hand, can lead to breathlessness and muscle weakness, which adds to feelings of fatigue.

Your local leisure centre may have suitable classes, such as yoga, where you can exercise in a gentle way under supervision, if you prefer.

So while it's important to stay active, you need to stay within your own limits.

And if you're having a more difficult day with your fatigue, your exercise might just be moving to and from the kitchen or up and down the stairs. Don't feel guilty about this. You may feel able to do more tomorrow or later in the week.

Try to find a type and level of exercise you can manage and would enjoy doing most days of the week.

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

thebraintumourcharity.org/living-with-a-brain-tumour/health-fitness/benefits-of-exercise/

Keep your mind active, if possible

Puzzles, such as jigsaws or Sudoku, can help to stimulate your mind. And some people say that activities, such as gardening or arts and crafts, help them to feel mentally refreshed.

Research suggests that a key part of physical fatigue may be mental fatigue, so getting back to some normality and engaging in interests, activities and hobbies, if possible, can be helpful.

Have a regular sleep pattern

It's important to get a balance of activity, rest and sleep. Try to have a regular sleep pattern.

For some, this can mean trying not to sleep during the day. This can leave you feeling more groggy. For others, it could mean having a regular nap during the afternoon.

Other things that help aid restful sleep include:

- avoiding caffeine and alcohol close to bedtime
- having your bedroom at a comfortable temperature
- avoid using back-lit devices and screens 1-2 hours before going to bed.

These include many smartphones, laptops, some e-readers or TVs.

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.

(Most more modern devices can be set to night-mode, which reduces this blue light.)

If, after 30 minutes, you find that you're 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.



Heather's story

"At first, I used to try and force myself to stay awake and keep moving, because it just didn't feel like I should have to sleep during the day at my age.

"But, as time has gone on, I've tried to stop being so stubborn, to just accept that it's not my fault and to give in to my need for a nap. I now nap most afternoons and also some evenings too.

"If anyone is struggling with fatigue, listen to your body. Don't feel guilty about needing to rest or to have a sleep. It's not your fault - it's the unwanted guest in your brain."

Eat like a marathon runner!

Pasta, fruit and wholegrain 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 complex carbohydrates with vegetables, dairy and a small amount of protein.



If you have the energy to cook, try to use fresh foods. Over-processed or refined foods have less nutritional value and so provide less or only short-term energy.

Similarly, takeaway 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.

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.

Of course, if you can't manage 3 full meals a day, try to eat little and often - perhaps 6 smaller meals a day.

And while it's important to try and eat a balanced diet, there are also benefits to enjoying food. So have a little of what you fancy, especially if you're really struggling with eating enough.



For more information, please see our Diet, nutrition and brain tumours web pages/fact sheet: thebraintumourcharity.org/diet/

Make sure you're drinking enough - stay hydrated

Dehydration can lead to tiredness. It can also lead to feeling or being sick. Being sick causes a further loss of fluids and important minerals that your body needs. This can make you feel more tired.

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



Heather's story

"Fatigue hit me full force after my treatment, I have never known exhaustion like it. The simple things which I used to take for granted, such as brushing my teeth or texting a friend, left me so tired that it felt like I had run a marathon.

"Even though things have got better since then, I still suffer with fatigue every day.

"I have found that Vitamin B supplements help me a little, bananas are also good for a quick pick-me-up when I hit an afternoon slump but I'm unable to have a nap. Coffee and tea in moderation also help."

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 or herbal pillows, to be helpful. Alternatively, try relaxation groups, or exercises, such as yoga or tai chi.

Counselling can help with feelings of stress, anxiety or depression.

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

Manage pain

Some people with a brain tumour experience headaches and other pain. Fighting it can be wearing, making you fatigued.

As well as using painkillers, some people find that techniques such as relaxation and mindfulness help to alleviate pain and therefore help with fatigue.

Acupuncture can also be used to treat pain, but let your medical team know if you're having acupuncture.

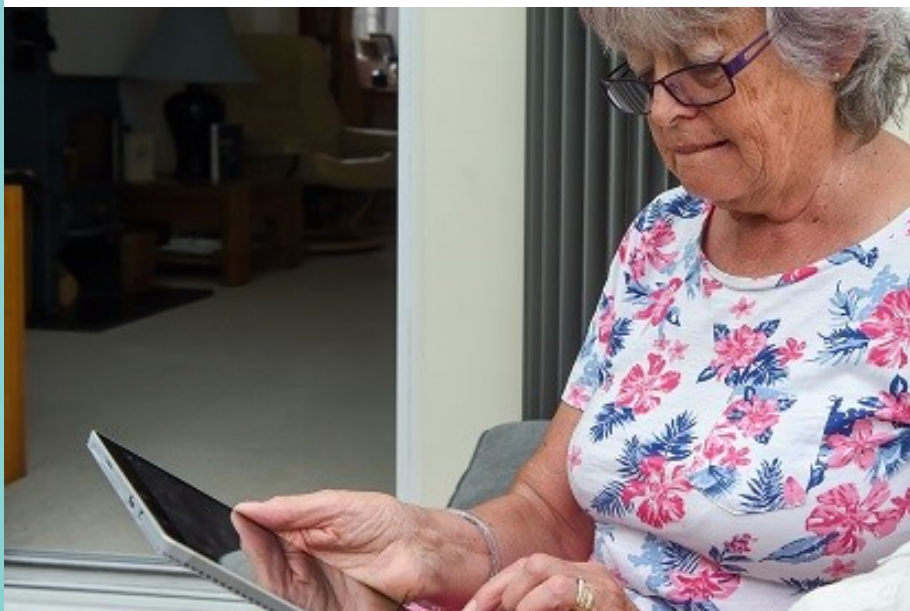
Find reputable information and talk about it

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

The Brain Tumour Charity continues to use best practice health information production guidelines to make sure that we remain a provider of high-quality health and social care information.

As well as the information in this booklet, you may find other information on our website about living with a brain tumour helpful in dealing with reducing side-effects that can have an impact on your fatigue.

thebraintumourcharity.org/living-with-a-brain-tumour/



How can I explain my fatigue to others?

Not everyone with a brain tumour will experience fatigue and those that do will experience it differently. For some, it'll 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 feel like an endless, draining sense of extreme, whole-body weariness. It can vary in intensity from day to day or throughout the day.

How is tumour-related fatigue different to the fatigue that someone without a tumour might experience?

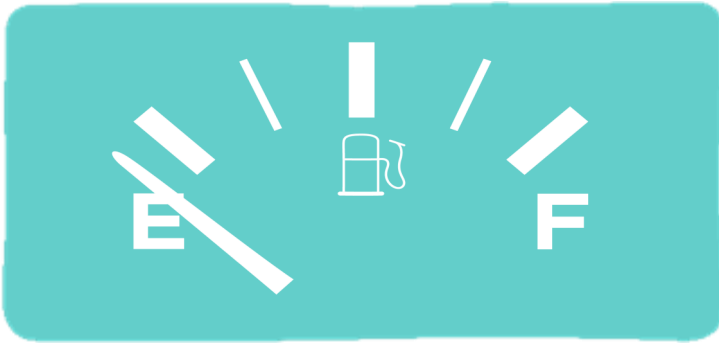
Tumour-related fatigue isn't usually relieved or improved by rest or sleep.

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



A rechargeable battery.

It runs down more quickly than before you were ill.



A car with a broken petrol gauge.

You know there's 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.

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

Friends and family, and even people with a brain tumour, therefore sometimes see fatigue as laziness, or wonder if the person 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. It can lead to difficulties in relationships, social isolation and loss or reduction in employment. This, in turn, can cause financial difficulties, extra stress and more fatigue.

What are the symptoms of fatigue?

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

- Lack of, or reduced, energy or motivation (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.



Carers

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:

thebraintumourcharity.org/being-a-carer/

Why am I getting fatigued?

The exact cause of fatigue isn't known, but it's thought there are several things that could contribute to it. Understanding these possible causes can also help you to explain it to others. They include the following:

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 these require a lot of energy.

As a result, your body is working harder, and some of the energy that you'd normally use on everyday living, is diverted to fight the tumour.

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

Your treatments

Surgery

Fatigue after any major surgery is very common, not just surgery on the brain. It's 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 impact 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) webpages and fact sheets:
thebraintumourcharity/cognition/
thebraintumourcharity/treatments/neurosurgery-adults/

Radiotherapy

It's very common to feel tired during your treatment. 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're making to and from the hospital.

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

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

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 usually gets better on its own over a few weeks without any treatment.

Occasionally, some people will have a delayed onset of fatigue, up to 5 years after radiotherapy treatment. You can contact your GP or healthcare team if this happens to you.



For more information, please see the Radiotherapy web page and fact sheet: thebraintumourcharity.org/treatments/radiotherapy-adults/

Chemotherapy

Many people experience fatigue following chemotherapy.

Chemotherapy can reduce the production of your red blood cells, leading to 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 needs energy to repair itself after treatment and that the immune system needs to adapt. This can drain energy as the body redirects its resources towards healing.



For more information, please see our [Chemotherapy web page and fact sheet:](https://thebraintumourcharity.org/treatment/chemotherapy-for-adults/)
thebraintumourcharity.org/treatment/chemotherapy-for-adults/

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. Some people find they become fatigued when they're withdrawn from steroids. For this reason, it's best to reduce the dosage gradually, but only do this under supervision of your doctor.

Speak to your doctor if you're 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.

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. As such, a vicious circle is created.



For more information, please see the [Cognition and brain tumours web page and fact sheet: thebraintumourcharity.org/treatments/cognition/](https://thebraintumourcharity.org/treatments/cognition/)

Seizures

Around 60% of people with a brain tumour will experience a seizure at least once. **You're 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, please see our Seizures (epilepsy) and brain tumours web page/fact sheets: thebraintumourcharity.org/treatment/adult-signs-and-symptoms/seizures/

Stress, anxiety and depression

Living with a brain tumour of any grade can cause a huge amount of stress and anxiety. The stress and anxiety caused by the diagnosis and the uncertainty it brings, uses a lot of energy and can affect quality of sleep, leading to fatigue.

Stress and anxiety is also common in people with low grade brain tumours, who may be on watch and wait (active monitoring).



See the Watch and wait (active monitoring) web page and fact sheet for more information.

thebraintumourcharity.org/watch-and-wait/

Some people living with a brain tumour experience depression, which can also leave you feeling physically and mentally exhausted.

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



For more information, please see the [Depression, low mood and brain tumours web page and fact sheet:](https://thebraintumourcharity.org/treatments/depression/)
thebraintumourcharity.org/treatments/depression/

Diet

The side-effects of brain tumour treatments can cause a vicious circle.

They include:

- feeling nauseous or being sick
- constipation
- changes in your sense of smell or taste.

These 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're taking in fewer calories. If the calories you're taking in are less than those you burn, it can leave you feeling very tired. Sometimes you may feel too tired to cook or eat. So the cycle starts again.



For more information, please see our Diet, nutrition and brain tumours web page/fact sheets: thebraintumourcharity.org/diet/

Dehydration

Dehydration happens when you don't have enough fluids in your body. This can happen if you're 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. Being sick leads to a further loss of fluids and electrolytes, making you feel more tired.

Pain

Some people living with a brain tumour experience pain on a daily basis, such as 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.

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's evidence that the levels of cytokines are higher in some tumour patients, possibly due to the body fighting the tumour.

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

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

Notes

Notes

About this information resource

All of our information is produced using robust processes, which follow best practice and quality guidelines of health information production, to ensure accuracy and reliability.

Written and edited by our experienced Information and Support Team, the accuracy of medical or other specialist information in this resource has been verified by leading professionals specialising in relevant areas of expertise.

Our information resources have been produced with up-to-date, reliable sources of evidence, as well as the assistance of members of our community, to make sure it makes sense to everyone and includes the information they want to see.

We hope that this information will complement the medical or social care advice you've already been given. Please do continue to talk to your healthcare team if you're worried about any medical issues.

If you'd like a list of references for any of our information resources, or would like more information about how we produce them, please contact us.

We welcome your comments on this information resource, so we can improve. Please give us your feedback via our Information and Support Team on 0808 800 0004 or [**support@thebraintumourcharity.org**](mailto:support@thebraintumourcharity.org)

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About The Brain Tumour Charity

Going further for a cure

As the UK's leading brain tumour charity, we're here to accelerate a positive change in how people affected by brain tumours are diagnosed, supported and cured.

At The Brain Tumour Charity, we believe that no-one should have to live with a brain tumour or lose a loved one to a brain tumour. Advances in both treatments and quality of life care need to be made - and they need to be made quickly.

We know that if we put our heads together, we're more than up to the challenge. So we're building a movement of people from every walk of life - all coming together to accelerate a cure.

Find out more and get involved:
thebraintumourcharity.org



**WE'RE
HERE FOR YOU
AT EVERY STEP**

thebraintumourcharity.org

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