brainstrust
the brain cancer people

my fatigue book

A resource to help you understand, manage and own fatigue – when living with a brain tumour

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About this resource

"I thought I knew what it meant to be tired. I now know I had no idea. This isn't just being tired. This saps at your identity, your confidence, your way of being. I don't go out anymore. I avoid leaving the house, I don't shop, friends have stopped asking me out."

Patient

Fatigue is one of the biggest challenges facing patients and caregivers who are living with a brain tumour – you have told us it is. Not only that, but research tells us it is.[1,2] It is one of the key themes that have emerged from our daily interactions with everyone in our brain tumour community, whether they are a patient, a caregiver, a clinician, a nurse or an allied health professional.

Fatigue caused by a brain tumour and treatment can be very different from fatigue caused by other cancers. More on this later.

1 MacDonald *et al.* (2015).

2 Day *et al.* (2022).

What this resource aims to do

This is an informative resource written to enable patients and caregivers living with a brain tumour to understand what is meant by fatigue and to self-manage fatigue relating to brain tumours so that they:

- learn a new pace of living
- take steps to mitigate the impact of fatigue
- make the most of what they can do, rather than focus on what they can't.

It provides an overview, along with suggestions for coping strategies. It is a game of two halves. The first half provides the background for fatigue – what we mean by fatigue, why patients get fatigued and the challenges of living with fatigue as patients and as caregivers. By becoming familiar with this resource, you should come away knowing more about:

- what we mean by fatigue
- the causes of fatigue
- what is different about fatigue for people living with a brain tumour
- how we measure fatigue
- coping with fatigue in different contexts.

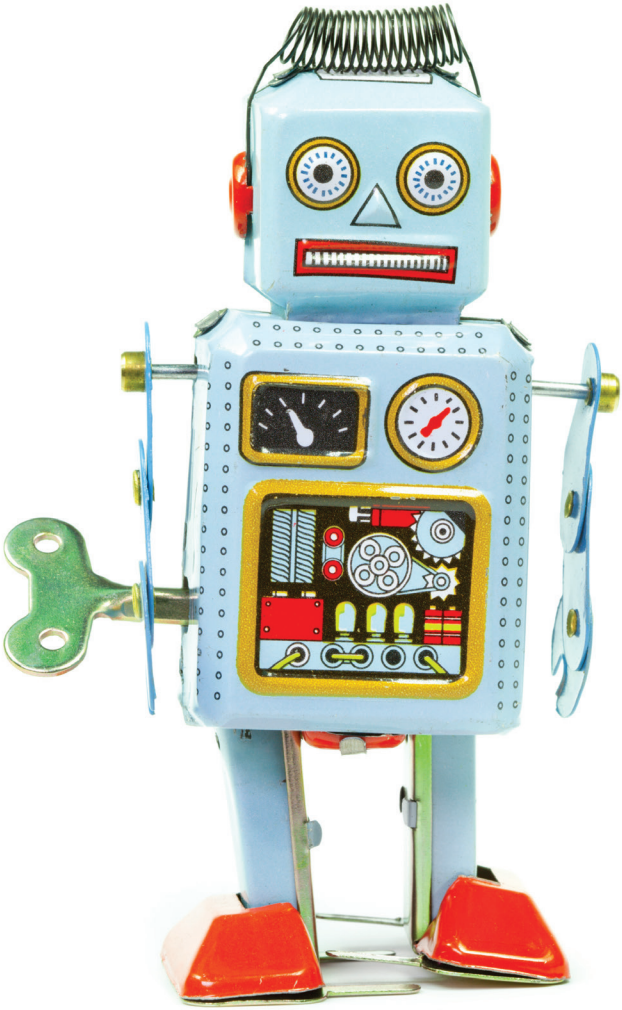
The second half is about building a personalised fatigue toolkit to help you manage fatigue so that your quality of life improves. This section covers:

- using a fatigue diary
- sleep hygiene
- self-activation strategies (including relaxation, mindfulness, prioritising, activity scheduling, acceptance, exercise)
- goal setting
- drug treatments for fatigue
- looking after someone who has fatigue
- who can help
- questions to ask.

As ever, if you have any concerns, ask your clinical team for advice.

Part 1:

Understanding fatigue



What we mean by fatigue

Fatigue is a physical, emotional and/or mental tiredness that does not go away completely. It is often experienced as overwhelming. It is very different from everyday tiredness, because it lasts longer and can come on without warning. It has a big influence on everyday activities and can make even small chores or routine tasks seem impossible to do.

I would have a shower and then have to go back to bed. I just couldn't do anything more.

Patient

Fatigue can last for a very long time (months to years), even after completing treatment for a brain tumour. Fatigue is known to be one of the most difficult side effects of brain injury and cancer treatment. It is not known exactly how many people living with a brain tumour suffer from fatigue, but it is estimated that between 40% and 80% of people with a brain tumour experience severe fatigue.[3,4] This wide range reflects genuine differences between studies and patient groups, rather than any resolution of the uncertainty. What more recent research does confirm is that fatigue (sometimes described as 'lack of energy') remains one of the most consistently reported symptoms across brain tumour types, and that fatigue levels can fluctuate significantly, particularly around the time of surgery.[5]

Causes of fatigue

We don't know the precise causes of fatigue. Because of the physical, emotional and mental aspects of fatigue, the cause is likely a combination of factors (also called *multifactorial*).

3 Struik *et al.* (2009).

4 Valko *et al.* (2015).

5 Hao *et al.* (2025).

Chemotherapy and radiotherapy can cause fatigue, but there is not much evidence to suggest that a brain tumour or its location alone can cause fatigue. It may just be that there is a problem in the brain that is causing fatigue. Fatigue can be associated with any brain injury, whatever the cause (e.g. stroke, trauma, inflammation or tumour) and wherever the location within the brain. On top of that, pain and certain medications, such as anti-epileptic drugs, can cause fatigue. Emotional side effects of any cancer treatment, such as worrying, feeling anxious and depressed and having trouble sleeping, can make fatigue even worse. If you think you have fatigue, you should have a thorough medical evaluation to identify possible reasons for this. Sometimes addressing other issues can reduce or even eliminate fatigue.

What is different about fatigue for people living with a brain tumour?

Because fatigue is common after cancer and after brain injury, people living with a brain tumour may be especially vulnerable to fatigue. People living with a brain tumour are much more likely to be treated with medications that have fatigue as a side effect, such as anti-epileptic drugs. In addition, people who have lived through brain injury often have more trouble processing a lot of information at the same time – for example, when in a room where more than one person is talking. Social events can become exhausting.

People living with a brain tumour can also feel drowsy or abnormally sleepy. Although this is related to fatigue, it should be seen as a separate symptom. Drowsiness can be caused by the tumour leading to an increased pressure within the skull, but it may also be a side effect of certain medications.

Treatment-related causes can include the following.

Surgery and anaesthetics. Fatigue occurs for up to one to two years after most major surgeries, not just brain surgery.

Radiotherapy. This can cause fatigue at any time during and after treatment, including a delayed response. For example, radiotherapy can cause an underactive pituitary gland as a late effect, leading to low thyroid-stimulating hormone or low cortisol production.

The combination of fatigue and the impact on cognition is sometimes called 'beamo-brain', but it is hard to tease out the symptoms. For more information about radiotherapy, visit www.brainstrust.org.uk/radiotherapybook.

People warned me that four to six weeks after the treatment has finished, I would feel really tired. This lasted about a month; having a shower was a supreme effort and I had to lie down afterwards. A course of radiotherapy is the equivalent to having another round of major surgery. Listen to your body.

Patient

Just how long does the radiation fatigue last? I appreciate everyone is different, but Dean is nearly fifteen months post treatment and is bone-tired most days. He is tapering his steroids, which we know can be tiring, but he is totally fed up now and so wants to feel more like his old self.

Caregiver

Chemotherapy. Chemo-brain is a known phenomenon (www.brainstrust.org.uk/chemotherapy). This is a loss of mental sharpness associated with fatigue. It can manifest itself in an inability to concentrate or multitask.

Withdrawal of steroids. Fatigue can be one side effect of stopping steroid treatment, which is why these should never be stopped abruptly but tapered.

Other factors include the following.

Attentional fatigue. This describes the tiredness that comes from having to focus on behaviours that used to be second nature, such as needing to focus on information or tasks. They *were* easy; now they require greater effort and concentration and sometimes need to be relearned. This causes slowed thinking and mental exhaustion. Sometimes people lose the ability to focus on several things at once; being in a noisy or busy place can cause stress, which in turn causes fatigue.

Epilepsy, which can come with a brain tumour. This is due to a range of reasons. For example, sometimes seizures disturb sleep patterns. The side effects of some anti-epileptic medication can also include fatigue.

A sense of urgency to get things done, trying to live at one hundred miles per hour – tiring factors. This sense is heightened with a serious illness, when you believe you might not have the time ahead that you thought you had.

I get tired because when I am having a good day, I try to pack everything in and live every second because it counts. But I can't do this anymore, and when I do, I pay for it.

Patient

Other factors can include depression, anxiety, physical impairment or disability, pain, low hormone levels, poor nutrition, dehydration and infection. Many of these are potentially treatable causes, and addressing them can relieve fatigue.

How do we measure fatigue?

This is tricky to answer. How do you know if you are fatigued and not simply tired?

These are the key signs:

- feeling anything from mild tiredness to total exhaustion
- feeling drained
- resting does not make it go away completely
- having no energy or strength
- feeling dizzy or light-headed
- finding it hard to do routine tasks
- lacking motivation
- finding it hard to concentrate
- finding it hard to think or speak
- low sex drive
- finding it hard to cope with life
- difficulty in managing your feelings.

There are other measurement tools that are used by hospitals for clinical and research purposes. These include the Brief Fatigue Inventory and the Fatigue Self-Management Scale. You might find it useful to look at the Brief Fatigue Inventory to get an idea of the kind of questions that you would be asked (page 55). By categorising your levels of fatigue using a 0–10 scale (0 = no fatigue, 10 = the worst fatigue imaginable) in this kind of tool and keeping a diary, you will be able to see how things improve or become worse over time.

A fatigue diary can help you to see patterns in your fatigue. For example, perhaps you notice your fatigue is worse after large meals or in the afternoon but better after an hour's rest. Do certain activities make you more tired than others? It might be helpful to fill in your diary with a healthcare professional or your caregiver. A typical diary can be found on page 44.

You are not alone

If you recognise these signs, please know that you are not alone, and that this is not 'just' tiredness. A 2024 study interviewed 40 people (24 people living with a brain tumour, five caregivers and 11 healthcare professionals) about their experience of cancer-related fatigue.[6] Across all three groups, the clear message was that this fatigue is different: it touches every part of daily life; it is often invisible to others, and people gradually build their own ways of coping with it, alongside advice and support from those around them. This matches everything you have told us, and everything this resource is designed to help you build for yourself.

Coping with fatigue in different contexts

What does it mean to cope with fatigue? It is pervasive and impacts in a variety of ways – physical, social, concentrative, emotional, spiritual. All the things that enable us to be who we are. What does this look like?[7]

6 Campbell *et al.* (2024).

7 Conn-Levin (2008).

Physical:

- reduced energy level
- diminished strength or endurance
- difficulty sleeping.

Social:

- changes in roles or relationships
- altered responsibilities within the family
- reduced ability to perform job responsibilities
- changes in sexual relationships or sexual response
- reduced interest in affection.

Concentrative:

- difficulty concentrating
- inability to understand new information
- being distracted by sensory input (i.e. noise, activity, etc.)
- feeling overwhelmed by daily tasks
- finding that typical activities of daily living are more difficult to do.

Emotional:

- changes in mood
- reduced feelings of self-esteem or confidence
- diminished sense of control about daily life
- fears or anxiety about the future
- concerns about body image (i.e. facial differences, hair loss, etc.).

Spiritual:

- questioning one's purpose
- disinterest in previous religious or spiritual practices
- feelings of 'Why me?' related to diagnosis
- indifference about prayer, meditation or other mindfulness.

You may be fatigued in one or two of these areas or in all of them to different degrees. Once you understand how fatigue is impacting on your well-being, you can begin to take steps to address it.

Part 2:

Analysing your fatigue

"I'm four months post op and want to know if this fatigue is part of the recovery. I ask because I spend way more time asleep than I do awake, and my clumsiness is off the scale at the moment. I can't help but feel that something is not quite right with me."

Patient

What follows is a series of checklists, things to do and things to try, that will help you to **analyse**, **identify** and **manage** your fatigue. This will create a toolkit that is personal to you. Only you can own your fatigue, and therefore only you can work out what you need to do. You can, however, ask for help. By building your toolkit, you will be more focused in your ask for help.

How does this resource work?

We use the principles of marginal gains. In 2010, Sir David Brailsford faced a tough job. No British cyclist had ever won the Tour de France, but as the new general manager and performance director for Team Sky (Great Britain's professional cycling team), that's what Sir David was asked to do. His approach was simple: Sir David believed in a concept that he referred to as the 'aggregation of marginal gains'.

As with Team Sky, there is no magic wand, no silver bullet that will spirit away your fatigue. It's so easy to overestimate the importance of one defining moment and underestimate the value of making better decisions on a daily basis. Almost every habit that you have – good or bad – is the result of many small decisions.

So if you improve every area related to your sleep by just 1%, then the small gains will add up to remarkable improvement. Start by optimising the obvious things: your environment, adjusting your pace of living, your habits before you go to bed. Then search for 1% improvements in tiny areas that are less obvious and harder to define. This resource will help you to search, analyse, deal with and manage your 1% improvements everywhere.

Analysing your fatigue

Treat yourself to a beautiful notebook, one that makes you want to pick it up and open it.

Remember that everyone is different. So the way you choose to manage your fatigue will work for you but probably not for someone else. You will find that people will tell you how to manage it, and this can irritate. You own this – it is your fatigue – and remember they are just trying to be helpful.

By **analysing** your fatigue, you can find strategies to manage it. But this on its own can be a daunting, tiring task, so see who can help you to do this. And take your time – you don't have to gather the data over a day. Take a couple of weeks, or even a month. This way, you will also have a more comprehensive view of your fatigue and how it impacts on your life. Keep a diary, complete the inventory, talk with your caregiver about what they notice. For example, if you share a bed, your partner may be aware of things about your sleep patterns that you don't notice. Complete the diary every day for two to four weeks. Make sure you capture the good days and the bad days.

Where to begin?

You might find it useful to use a scoring system, where 1 reflects very low levels of fatigue and 10 means your fatigue is off the scale. These are the things you might want to capture:

1. Describe last night's sleep.	How well did you sleep? How did you feel when you woke up? Did your partner notice anything about your sleep patterns?
2. Describe your activities.	List your activities during the day. Note how long each activity lasted and the type of activity. The more detail you include, the better.
3. Describe how tired you feel when you do an activity.	Is it an activity that you coast through, or is it one that you find challenging?
4. Add any other information.	Make a note of other factors you notice that impact on your sleep – for example, alcohol consumption, getting too hot, eating certain foods. Also, log things that have a positive effect, e.g. having a cooler bedroom, being in the dark.

Using a fatigue diary

Capture as much information as you can. This will help you to identify what might be making your fatigue worse or better. You can then complete the diary again once you have made changes and compare the two to see if the changes have made a difference. Think about marginal gains – they might seem to be insignificant, but if you make two or three changes, the impact could be big. Try to give as much information as you can. This will help you identify what helps and if there is a pattern.

You can photocopy the diary (it's also on page 44) so that you have blanks to complete. Or download it from the *brainstrust* website at www.brainstrust.org.uk/fatiguediary.

Time	Activity	Scale of fatigue 0 = no fatigue 10 = severe fatigue	What helps
8.00	Showered, ate breakfast. Had to go back to bed.	8. If I couldn't have got up at all, it would have been 10.	Accepting that I am fatigued and showering at a different point in the day. Maybe before I go to bed.

Dealing with things that don't help your fatigue

Analysing your fatigue is the easy bit. Now you have done this, you should be able to see what is adding to it and making it worse.

Sleep hygiene

I'm really struggling to sleep, even if I'm exhausted! Even if I do nod off, I only doze, really. I'm on a very high dose of Keppra, so do have to be careful.

Patient

What disturbs your sleep? It seems counterintuitive to suggest that sleep may be adding to your fatigue, but lack of sleep may be one cause. Complete the checklist 'Dealing with things that don't help your fatigue' on pages 45–47. Tick any that apply to you, and, using your 1–10 scale (1 being good, 10 being bad), identify which ones have the most impact. It's easy to say 'sleep hygiene', but harder to achieve it, as it may mean breaking habits of a lifetime. But you have had a life-changing diagnosis; nothing is as it was, so it's time to adapt. It becomes so easy – so comfortable – to keep current perspectives and opinions on things. But this restricts the capabilities of the mind, the ability to adapt. If there's one thing humans can do, it's adapt. We've been doing it since the beginning of time, and we will never stop.

So, what do we mean by sleep hygiene? It's about the things you do as bedtime approaches. And these will fall into good and bad things – you will be doing some of both. Use the checklist on pages 48–49 to see what you are doing that you need to keep doing, and what you need to stop doing or change.

Identify three things you will commit to changing. Gift yourself these things. These will be your focus for change. Write them here:

1 .....

2 .....

3 .....

Of course, your sleeping habits may be fine, but you are still fatigued. What else could you do?

Part 3:

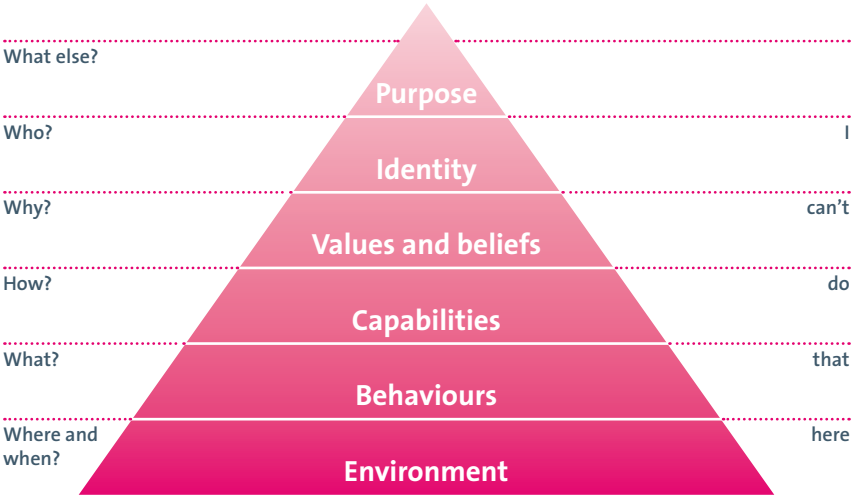
Managing your fatigue

You can now use your skills, knowledge and confidence to self-manage your fatigue. The next focus is on self-help measures. You have analysed your sleep, or lack of sleep, and identified the things that don't help and the things that do.

Goal setting: I can't do that here

We need to start with appropriate goals that fit with your values and context. Let's start with the why. *Why do you want to have less fatigue and manage the fatigue that you do have?*

We can create more lasting and sustainable change together, by working on your purpose, identity, values and beliefs. Have a look at the pyramid below. These higher levels in the pyramid are generally more 'invisible', harder to change and harder to assess, because they make you think about your thoughts, emotions and physical sensations. To make changes, we need to think about what motivates you, what your life would be like if you weren't fatigued, and what you need to do to have that life. Thinking about this will help you to explore what is stopping you making the changes you need so that you can achieve your goal of being less fatigued.



You can use this in other areas of your life too. 'I can't do that here' can be used to identify what is stopping you from doing something that is important to you:

I = identity

Can't = values and beliefs

Do = capabilities

That = behaviours

Here = environment

Reflective questions

Sit with someone close to you, and ask them to make notes while you answer the questions below. You don't have to answer all the questions, just the ones that will help you to think about you and your fatigue. Some of these questions might evoke emotion – that's okay. Emotion shows connection with what you are trying to achieve.

About me	Questions	Response
Purpose	What is life all about? What do I feel compelled to do? What do I want for me? What do I want for my family, friends, children, parents? What is this all about for me? What must I do? What would I like to be different for me?' What do I need to achieve? What would be a good outcome for me?	

About me	Questions	Response
Identity	What is my role? What have I lost? What has changed? What has my diagnosis told me that is important? What have I learned about myself since my diagnosis? What is my role in the family now?	
Values and beliefs	What do I now believe? What do I now value? What impact is being fatigued having on things that are important to me? How important is it to me that I make changes in my life? Do I allow myself to sleep/rest?	
Capabilities	What do I need help with most? What information do I have? What information do I need? What haven't I changed despite having the information? When do I feel out of my depth? What inhibits me making the changes?	

About me	Questions	Response
Behaviours	Where and when do I rest? How does my diet affect my situation? Where could I make changes? What changes can I make to my sleep hygiene? What further changes am I thinking about? What have I done already to reduce fatigue?	
Environment	What is in my environment that could help me? What am I tolerating in my environment? Who or what is exhausting? Who is close by and can help me? Where am I able to rest? Who, what or where is my sanctuary? What replenishes me?	

Self-activation strategies

Self-activation strategies are actions that will help you to make the changes you want so that you own your fatigue.

Remind yourself of your goals – the three things you have committed to change. Rewrite them here:

1 .....

2 .....

3 .....

What follows now are some activities you can do. Choose the ones that will help you to achieve your goals.

Relaxation

Relaxation doesn't just happen. You will need to develop your body's ability to relax through breathing or physical relaxation, or both. If you are not used to gifting yourself the time to relax, start to build the skill of relaxation when you are relaxed, rather than when you are stressed. It is a skill to be learned, and like any new skill, it will take time.

Breathing

1. Choose a space that is quiet and warm and not too bright. Set a timer for five minutes.
2. Lie on your back, arms by your sides, palms facing upwards. Let your feet fall out naturally. If you are uncomfortable lying down, then sit in a comfortable chair.
3. Bring gentle attention to your breathing. Close your eyes. Otherwise, you'll be spotting cobwebs and other things that distract.
4. Breathe slowly and steadily and deeply – in through your nose and out through your mouth. Breathe into your belly, rather than your chest, and let your belly rise and fall as you breathe. You can place a hand on your belly, just below your ribs, so that you can feel the rise and fall.
5. Breathe in for three counts and out for five counts.
6. Pause between each breath.
7. Notice how the air feels and how your body moves as you breathe in the air.

Physical relaxation

This builds on relaxing by breathing. Follow steps 1 and 2, then:

3. Bring awareness to your body. Starting from the top of your head, work all the way down your body to your toes. As you pass over each part of your body, label it, then soften and relax it.
4. Let the tension go in each body part – forehead, eyes, jaw, neck, shoulders, etc. Pay particular attention to the areas where you tend to hold tension – neck, shoulders, jaw, forehead, scalp.

Mindfulness

Putting your day to bed.

There is a transition point in every day when the day's activities end and the evening begins. Use this time to think about the day that has just passed. Find a quiet space to reflect. Take fifteen minutes, and in your beautiful notebook, capture the following:

- What have you achieved today? It doesn't matter how small; note this down. Be kind to yourself and champion yourself. Who else deserves to be championed? Make sure you let them know.
- What loose ends are there? You might not be able to tie them all up here and now; just acknowledge that they are there. When might you deal with them? Who can help you? Once you have done this, put them to bed until you are ready to deal with them.
- What might stop you sleeping well tonight? What positive actions might you take to deal with this? One of the things you can do with negative thoughts is to accept them, acknowledge that they are there, and then let them go. This is the brain processing. Just let them go, and bring your mind back to the task at hand.

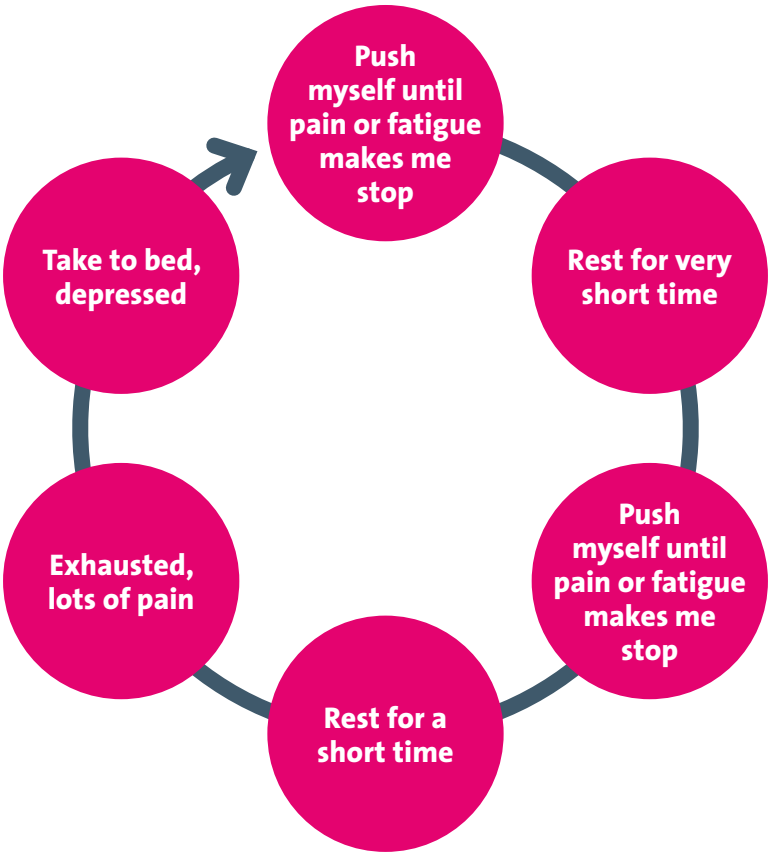
After fifteen minutes, put your notes to one side and enjoy your evening.

Learning a new pace of living

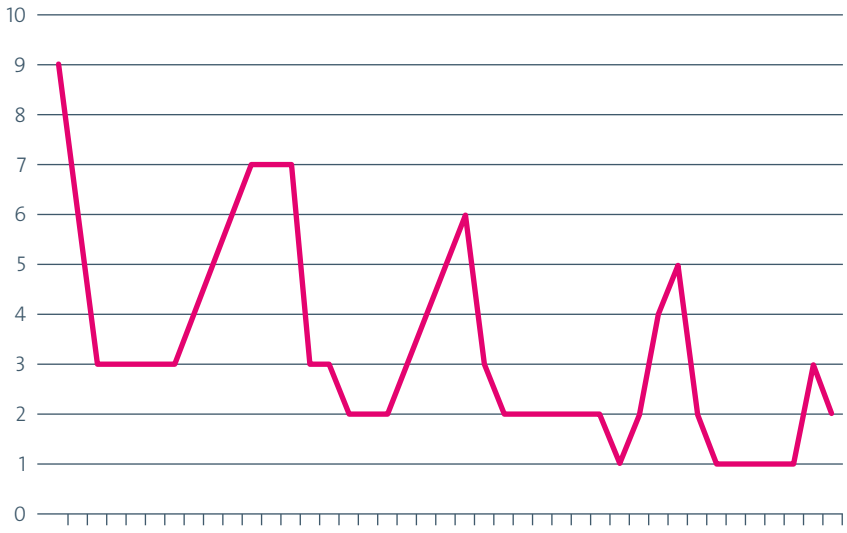
Pacing is not about doing everything all at once. Pacing is about prioritising tasks and planning activities, and taking a break *before* you need one. This will enable you to self-manage better and build resilience, something that is depleted when you are fatigued. You may have heard the term 'boom and bust'. This is a good way to describe how it feels when you don't pace. We all tend to boom and bust to some extent. We have days when we really push the boat out to achieve something important to us, and then feel tired for a while afterwards. If our health is robust, we can cope with

these peaks of exertion. However, a lifestyle where we constantly push ourselves beyond our capacity and make little time to recover eventually takes a toll on our health, as our immune system in particular becomes depleted.

If you are already challenged by a health condition, the contrast between your activity levels on good days compared with bad days can become more marked and extreme. This then creates a problem – a vicious circle. It can look like this:



Or like this:



A boom is a day when you feel a bit more energetic. You might try to make up for lost time by packing in as much as you can. You might enjoy the sense of achievement so much that you become unaware of, or ignore the signs of, fatigue or increased pain. It is almost as if your mind takes over, racing ahead as your body is left behind.

At this point, you are expecting too much of your body, which may not be able to deliver what you are asking of it. Your muscular and circulatory systems may be challenged. You may not have the ability your mind expects, due to your health condition.

Inevitably, you crash and need to rest to recover. This is the bust phase. Sadly, as you enter an extended spell of inactivity, you are further reinforcing the process of deconditioning, losing strength and stamina. Mentally, it becomes harder to recover. Over time, this can become a difficult downward spiral, as you find that you need to rest more to achieve less.

Just recognising this pattern of boom and bust will help you to break it and pace yourself a little differently. Some of the strategies explored here will help to break this cycle.

Creating a sanctuary

Think about creating a space that truly is a sanctuary for you. What does this look like? It doesn't have to be exotic, expensive or a room on its own. It could be as simple as designating a space in the kitchen where electronic devices are plugged in when you come into the house in the evening. It could be turning off the TV and turning on some relaxing music instead. It could mean stopping what you are doing to make eye contact with your children while they talk to you. It could be saying no to some plans so that you can spend time together as a family, or time on your own. A sanctuary is a space where you can breathe, take a break from performing, and where you can be who you are in a safe place.

Prioritising

Often when we are fatigued, or even just plain tired, things that we would normally deal with become overwhelming, and then we feel unable to cope. This sets off a cycle of negative chatter – the more we feel overwhelmed, the more fatigued we feel. It's easier to give up than catch up. Prioritising activities means that you can save your energy for the things that you need and want to do. This might also mean letting go of some of the things that you can't do, or finding workarounds. This activity will help you work out what to do. You need a notebook and four different-coloured highlighters.

In your notebook, list all the activities you do in a typical day. If you have enough energy, do it for the week. Work through your list, highlighting in different colours:

1. which are important to you
2. which you'd rather not do
3. which could be done less often
4. which don't really need to be done at all.

Now look at the list of activities that are important to you. What would happen if they didn't get done? Are there any you could just let go, or move to a different category?

Could any be done in a more energy-efficient way?

Could they be done at a different time? Or even less often?

Can anyone help you with these activities?

Activity scheduling

So, now you have your list of 'must-dos', your priorities. Now that you know what these are, you can plan your time more effectively. This might seem like overkill, but by doing this, you will also be able to plan for some downtime, particularly if you have noticed that your fatigue happens around the same time every day. You'll also be able to manage your energy levels more. Instead of doing two activities back to back, you can build in an airbrick and have a rest, either before or after or both.

Golden rules:

- Balance your day between easier and trickier tasks, and build in rest breaks.
- If you have a heavy task to do, break it down into smaller chunks. Do it a bit at a time. For example, if you want to walk the dog, plan to walk to a dog-friendly cafe or a friend's, where you can break your walk. Or even consider walking to a bus stop and then catching the bus back. Dogs like variety!

Pleasurable activities

In the busyness of our lives, sometimes we lose sight of pleasure. We are so busy trying to sort, manage, orchestrate, drive that we forget that we need a balance. Make a list of things you like to do that make your heart sing. These will give you energy. Many do not use much energy; many are actually quite small things, like sitting with a favourite piece of music or feeling the sun on your face, listening to birdsong or having a cuddle. Page 54 has plenty of suggestions. Write yours in your beautiful notebook. Look at them often to remind yourself. And promise to do one every day.

Organising your environment

This may seem obvious, but sometimes taking a fresh look at where things are in your space and moving them can make you more efficient. This means you will have more energy for the important things you need and want to do.

Think about:

1. Keeping things you use regularly within reach so you don't have to keep getting up and down.
2. Doubling up on some things to save time. For example, having a charging cable for your mobile phone or laptop in every room (but not the bedroom!) where you tend to use your phone/laptop can save time and energy. You don't have to remember where your chargers are or keep moving from one room to another to keep your devices charged.
3. Putting lightweight things that you rarely use in higher cupboards and heavier things that you often use in easier-to-reach places, e.g. dinner plates.
4. Decluttering! Just the act of walking into an uncluttered room can be energising.

Exercise

There is growing evidence to show that exercise can help your body work at its best when you are living with a brain tumour.[8] Exercise can improve strength, fitness, mood and general well-being, and a UK pilot trial specifically for fatigued brain tumour patients, combining lifestyle coaching with behaviour change support, found encouraging early signs of benefit.[9]

But exercise isn't always straightforward when you have a brain tumour. The brain controls voluntary movement, balance and gait, all essential elements of physical activity. When the brain's occipital lobe is affected, some vision can be lost as well, making mobility more difficult. In addition, therapies can cause fatigue, dizziness, weakness and lack of balance, making the situation worse. Long-term use of steroids, which may be given to counteract chemotherapy side effects, also causes muscle wasting. Therefore, exercise may be particularly difficult for some people living with a brain tumour. Equally, exercise may bring real benefit, and the type of exercise you choose may matter.

The best current evidence, from a 2026 review pooling 15 studies in people with primary brain tumours, suggests that combining aerobic exercise (such as walking, cycling or swimming) with resistance/strength exercise gives the most consistent benefit for fatigue.[10] Aerobic exercise on its own also showed a clear benefit for sleep quality. Resistance exercise on its own showed more mixed results, so it's worth trying to build both types in together where you can, rather than relying on just one. Yoga and Pilates have also shown promise for fatigue in individual studies, so these remain good options too, particularly if balance or intensity is a concern.

8 Ruden *et al.* (2011).

9 Rooney *et al.* (2022).

10 Ntalagianni *et al.* (2026).

The most important thing is to do what works for you and what you can build into your routine. Walking is easy to build into daily activity. Others choose yoga, tai chi, cycling, swimming or dance classes, like Zumba.

If balance is a problem, exercises can be done while sitting down. Or practise standing while lightly holding on to a kitchen worktop or heavy piece of furniture. Let go of it intermittently, but stay close enough so you can grab it again if you need to.

Movement is more effective than standing still. For instance, it's generally better to raise yourself up and down on your toes repeatedly, rather than to practise balancing on one leg.

Exercise in short sessions for three to five minutes a few times a day rather than for longer single sessions to begin with. Then build up as you're able – ideally, combining some aerobic activity with some gentle strength work.

Add gentle stretching exercises to your regimen. Yoga is great for building strength and for relaxation.

The easiest, cheapest form of exercise is going for a walk. The payback is huge, but pace yourself. If you haven't been for a walk for a while, set a realistic goal of five minutes, and gradually increase the time until you are walking for thirty minutes. Walking will help you to:

- maintain a healthy weight
- increase your energy levels
- prevent or manage various conditions, including heart disease, high blood pressure and type 2 diabetes
- strengthen your bones and muscles
- improve your mood
- improve your balance and coordination
- be happy.

Rest

The antithesis of exercise. What does rest look like for you? It means different things for different people and is never a case of one size fits all. Rest is important. It stops you getting to the point of exhaustion, so that you have to stop what you are doing, regardless of what you are doing. Planning for rest is a critical part of fatigue management. By planning your activities, you can plan to rest too. Only you know what type of rest break works for you, for how long and when. It could be:

- a few short rests, or power naps
- one longer rest at the same time each day
- resting between activities.

Try not to nap after 3 p.m., and only nap for up to twenty minutes. The quality of rest is key, though. Try to make your rest as complete as possible. This means aiming to switch off your mind and body and, more importantly, asking those around you to understand how valuable this time is for you. You need to be quiet and undisturbed.

Diet

We've talked about sleep hygiene, which includes things like not eating a heavy meal before bed and avoiding fizzy sugary drinks and coffee. Planning five or six meals throughout the day might help. A combination of a sensible diet (food from all groups – lean protein, complex carbs and a small amount of healthy fats), rest and exercise can help maintain a healthy weight and give you more energy. Diet is more than just food, though. Think about fluid intake too. Some people drink less to avoid going to the toilet, but being dehydrated can lead to fatigue.

Drug treatments for fatigue

There are currently no drugs licensed in the UK specifically for brain tumours and fatigue. Certain drugs (Amantadine, Modafinil) licensed for other conditions may be prescribed.[11] These drugs promote wakefulness but carry side effects.[12] However, there isn't much evidence to show that they can be effective,[13] and what evidence there is suggests that some of the fatigue management tools in this resource can be more effective.[14] You would also need to consider how drug treatments might interact with other medications you may be taking. There is also some evidence to show that taking vitamin D can help with the fatigue, but this is in otherwise healthy people. There is no evidence to show that this can be effective for people living with a brain tumour. To weigh up the pros and cons of drug treatments, you should discuss them with your neurologist or oncologist.

Research into new drug options continues. Early-phase trials are now exploring whether other approaches – for example, adding natural compounds such as marine-derived fucoidan to standard chemotherapy for glioblastoma – might help with fatigue.[15] These are still in the very early stages of testing, and none is yet proven or available outside a clinical trial, but it remains an active area of research, and it's worth asking your clinical team about any relevant trials that may be recruiting.

Acceptance

Acceptance helps us to accept the difficulties that come with life and what is out of our control, while at the same time committing to action that will improve our quality of life.

11 Boele *et al.* (2013).

12 Grant *et al.* (2016).

13 Lee *et al.* (2016).

14 Day *et al.* (2022).

15 Kong *et al.* (2025).

Life brings joy and pain, and learning the skill of acceptance – to accept things as they are without evaluation or attempts to change them – can bring freedom and help us to become 'unstuck'. It is about living with painful and negative thoughts and feelings, understanding that they are part of the unhappiness of the life challenges we are facing, and not being overwhelmed by them to the extent that we become trapped and unable to move forward in our lives.

Accepting that you are fatigued can allow you to move forward, whereas obsessively and unhappily playing things over and over in your mind keeps you stuck. So, for example, being frustrated and angry because you can't do the things you used to do may mean that your frustration and anger become the focus, and this is using energy you could be using more positively. Accepting the reality of your fatigue and working with what you have now, living in the present rather than constantly asking 'Why?' about the past, reduces helplessness and despair. It can open your eyes to new opportunities, new ways of doing things, new hobbies and new forms of exercise.

Acceptance means allowing the painful feelings and sensations to come and go as part of the natural process of loss, while dropping the struggle with them. By giving the feelings permission to exist in the present moment, but not getting caught up in them and being dragged back to the past, it becomes easier for your feelings to come and go without you getting stuck within them. And so, over time, they lose their impact on your everyday psychological and emotional well-being.

How to accept fatigue as part of your day

One way to do this is to use the metaphor of a sailing boat.[16] Imagine that life is like sailing a small sailing boat. During your life, you have picked up the skills necessary to sail your boat, and

16 Gillanders *et al.* (2026).

you have a sense of where you are taking this boat. At some point in your learning to sail, you have learned that from time to time, waves wash over the bow, and you will find yourself with wet feet. The usual response that people have learned is as follows: when you have water around your feet, use a bailer to bail out the water.

So you've learned about the bailer, but when it has not been needed, it has been put away in a locker, ready to be used if needed. And at some point along your journey, you have had waves come over your boat, and there is now water in the bottom of your boat. So you have started to do the thing that is sensible and logical to do: get rid of the water. You have been using that bailer a lot, sometimes bailing quickly, sometimes bailing carefully, sometimes bailing wildly, sometimes bailing desperately, and in your experience, have you managed to get rid of the water yet? And all this time that you have been bailing, what has been happening to the direction and progress your boat has been making? Is it fair to say that you have been bailing more than you have been sailing this boat?

Now, what if you were to one day really look at the bailer and see that it is full of holes? What if it were a sieve? What would you have to do first? You'd have to find a different bailer, one that is more effective. It may be that you have already tried different bailers, and none of them are effective any more. So, you need to develop a different approach to the water in your boat. What if this approach could be about accepting that there will always be water in your boat, and the time has come to put a hand on the tiller and choose to pull in the sails and get the boat moving in whatever direction you choose? Once you get the boat moving, then you might be able to investigate some other ways of bailing, if they prove to be useful strategies in helping you to take this boat where you want it to go.

The question to ask yourself is this: which would you choose?

1. To have a boat with only a little water in the bottom, but the boat is drifting because you are bailing so much and you do not have the capacity to look up to steer the boat. In other words, you are not choosing the direction you sail in.
2. To have a boat that has water in the bottom, maybe sometimes so much water that you wonder how it is still afloat, but you are taking this boat, however slowly, in the direction that you most want to take it.

Acceptance can allow you to move forward, whereas obsessively and unhappily playing things over and over in your mind keeps you stuck. Accepting the reality of living with fatigue and working with what you have now, living in the present rather than constantly asking 'Why?' about the past, reduces helplessness and despair over time. If you feel unable to adjust to fatigue or other consequences of having a brain tumour to a point where it is significantly impacting your day-to-day life, you may want to think about accessing professional support through *brainstrust* or your GP.

Part 4:

Looking after someone who has fatigue

I love it when my husband is tired. He goes to lie down, and so I get a break. And this makes me feel so guilty. We should be making the most of our time together, not enjoying space apart.

Caregiver

Fatigue can be unpredictable. Caregivers may have planned an event, only to find that they can't do it with their loved one, as the person is just too fatigued. So a key part of being a caregiver who is living with someone who has a brain tumour is to be agile and tolerant, accepting of uncertainty, and to manage expectations – their own and those of their loved one. This is quite a tall order when, as a caregiver, you are already digging deep. You may find yourself having to dig even deeper, but remember that you can build a team around you to help you. Things you can do include:

- giving the fatigued person more help if it is needed
- ensuring they have undisturbed rest
- offering to help; don't wait to be asked
- supporting them with a gentle exercise plan – for example, go for a walk together
- making sure they stay hydrated and eat healthily
- completing some of this resource for them if they are unable to do it for themselves.

Likewise, as a caregiver, you have a right to rest too. Being a caregiver is not a role you applied for, nor is it one for which you have had any training. You need to know your sanctuary, know how and who to ask for help, and be comfortable in gifting yourself the time to be the person you were before you became a caregiver. What is important to you?

Who can help?

That's easy. List the people who are in your team. These are people who you know would be only too happy to help out. People want to help. And you can help them by being specific in your ask. It's not always easy to accept help when it's offered, but give people the opportunity to step up to the mark. By asking, you will be helping them too. They want to be involved.

Questions to ask

Remember why you are asking. Asking is not a sign of weakness or helplessness. It's a sign of strength, of organisation, of wanting to get on with things.

Prepare a list of tasks that you'd like help with. Refer to the 'what makes your heart sing' section on page 54:

1. Which are important to you?
2. Which would you rather not do?
3. Which could be done less often?
4. Which don't really need to be done at all?

Which of these activities could people help you with? Break down the task. Which bits can you do? Which bits could someone else easily tackle?

Think about who you are asking and what their skill set is. Personal care might be better done by a close person. Cutting the grass and weeding, by someone who likes being outdoors. Collecting a prescription, by someone who is often in town and has access to a pharmacy.

Part 5:
My toolkit

Fatigue diary

Try to give as much information as you can. This will help you identify what helps and if there is a pattern. You can have this page photocopied so that you have blanks to complete. Or download it from the *brainstrust* website at www.brainstrust.org.uk/fatiguediary.

Time	Activity	Scale of fatigue 0 = no fatigue 10 = severe fatigue	What helps
8.00	Showered, ate breakfast. Had to go back to bed.	8. If I couldn't have got up at all, it would have been 10.	Accepting that I am fatigued and showering at a different point in the day. Maybe before I go to bed.

Dealing with things that don't help your fatigue

Tick any that apply to you, and using your 1–10 scale (1 being least impactful, 10 being most impactful), identify which ones have the most impact.

Cause	Comment	1–10
Pain	People with pain feel less control over their sleep, worry more about lack of sleep affecting their health and exhibit greater sleep sensitivity. When pain is first experienced, most people do not experience sleeplessness. However, when pain becomes a problem, it can be a vicious circle. If you experience poor sleep due to pain one night, you are likely to experience more problems the next night and so on. It gets worse and worse every night.	
Needing the bathroom	When you have a frequent urge to use the toilet at night, a good night's sleep can be hard to achieve. If you find yourself waking up to urinate more than twice each night, you may have a condition called nocturia. This can be caused by a variety of things: age, chronic urinary tract infections, drinking excess fluids (especially caffeinated and alcoholic ones) before bed, bacterial infection in the bladder and medications that encourage urination (diuretics).	

Cause	Comment	1–10
Insomnia	Symptoms of insomnia include: • difficulty falling asleep at night • waking up during the night • waking up too early • not feeling well rested after a night's sleep • daytime tiredness or sleepiness • irritability, depression or anxiety • difficulty paying attention, focusing on tasks or remembering • increased errors or accidents • ongoing worries about sleep.	
Too much caffeine	Because caffeine is a stimulant, most people use it after waking up in the morning or to remain alert during the day. Drinking caffeine close to bedtime can cause disturbed sleep.	
Noise	Whether you are sensitive to bumps in the night or sleep like a rock, sound has the potential to affect your rest and your health. Sound appears to have both positive and negative influences, depending on the type, noise level, personal preference and other factors. For example, gentle background noise can mask a noisy street, while a partner's snoring or creaky pipes can result in restless nights.	
Alcohol	Avoid alcohol close to bedtime. It can lead to disrupted sleep later in the night.	

Cause	Comment	1–10
Temperature	A cool bedroom is conducive to better sleep.	
Anxiety, depression	Low mood is not uncommon when dealing with a serious illness. And, of course, fatigue can affect your mood, so it becomes a self-perpetuating cycle.	
Light	It's only with the advent of electricity that we now need to seek out darkness. Electricity has fundamentally changed our relationship with light and dark and posed serious new challenges to sleep. Artificial light, inexpensive and ever-present, wreaks frequent havoc on sleep, without many people even being aware of its detrimental effects. The widespread use of digital technology – and the light emitted from all those screens – has introduced another highly disruptive challenge to sleep.	
Medications	Some drugs add to fatigue, e.g. anti-epilepsy medication.	
A partner	Does your partner wake you unintentionally?	
Infection	For example, colds, bladder infections and chest infections can cause tiredness. And if you are coughing during the night, this will disrupt your ability to sleep.	
Anything else?		

Sleep hygiene – how clean is yours?

Have a look at the list and tick the relevant boxes. Which do you do, and which don't you do? Don't overthink your responses; the first response is usually the right one. Positive actions can make you feel that you are owning your situation.

	Usually	Sometimes	Rarely
Things that can influence your sleep positively. Do you do any of the following?			
Go to bed at the same time			
Get up at the same time			
Exercise every day, preferably in the morning			
Get some exposure to bright or outdoor light in the afternoon			
Keep the temperature in the bedroom between 15°C (60°F) and 19°C (67°F)			
Keep the bedroom dark			
Keep the bedroom quiet			
Do a relaxation exercise just before going to sleep			
Have a warm bath or massage to relax muscles			
Keep your hands and feet warm			
Use cotton bed linen, a lightweight duvet and decent pillows			

	Usually	Sometimes	Rarely
Things that can influence your sleep negatively. Do you do any of the following?			
Use electronic devices before going to bed			
Nap during the day/evening			
Eat a heavy meal or rich food prior to going to bed			
Drink alcohol before going to bed			
Drink caffeine before going to bed			
Drink fizzy drinks before going to bed			
Exercise before going to bed			
Smoke before going to bed			
Go to bed hungry			
Tell yourself to go to sleep			
Engage with mental stimulation before going to bed, e.g. watching an exciting film, playing a computer game, having an argument			

Now list in the space below three things you can change to improve your sleep hygiene. Be realistic: set goals that are achievable and within reach. You can revisit and set new goals as you achieve them.

1 .....

2 .....

3 .....

Reflective questions

Sit with someone close to you and ask them to make notes while you answer the questions. You don't have to answer all the questions, just the ones that will help you to think about you.

About me	Questions	Response
Purpose	What is life all about? What do I feel compelled to do? What do I want for me? What do I want for my family, friends, children, parents? What is this all about for me? What must I do? What would I like to be different for me? What do I need to achieve? What would be a good outcome for me?	

About me	Questions	Response
Identity	What is my role? What have I lost? What has changed? What has my diagnosis told me that is important? What have I learned about myself since my diagnosis? What is my role in the family now?	
Values and beliefs	What do I now believe? What do I now value? What impact is being fatigued having on things that are important to me? How important is it to me that I make changes in my life? Do I allow myself to sleep/rest?	

About me	Questions	Response
Capabilities	What do I need help with most? What information do I have? What information do I need? What haven't I changed despite having the information? When do I feel out of my depth? What inhibits me making the changes?	
Behaviours	Where and when do I rest? How does my diet affect my situation? Where could I make changes? What changes can I make to my sleep hygiene? What further changes am I thinking about? What have I done already to reduce fatigue?	

About me	Questions	Response
Environment	What is in my environment that could help me? What am I tolerating in my environment? Who or what is exhausting? Who is close by and can help me? Where am I able to rest? Who, what or where is my sanctuary? What replenishes me?	

What makes your heart sing?

Which of these do you like to do? Highlight key ones and build them into your activity planning. Promise yourself to do one a day, as a minimum. Add your own.

Phone a friend	Paint your nails
Watch a favourite film	Treat yourself to something new
Have a massage	Light a candle
Curl up with a good book	Have clean sheets on the bed
Play word games	Thump a cushion
Enjoy a walk in the sun	Declutter a cupboard
Sit by the sea	Stretch
Watch people from a cafe	Make a list
Go out for dinner or have a takeaway	Do something new this week
Walk a dog	Have a bath
Watch a comedy	Look at photographs
Cuddle someone or be cuddled	Share a smile
Surf the internet	Plan a weekend away
Wear something cosy	Dance
Have someone wash your hair	Clear out an inbox
Tell someone what is special about them	Meet a friend for coffee and cake
Bake a cake	Plan a get-together with friends

The Brief Fatigue Inventory

This assesses the severity of fatigue and the impact of fatigue on your daily functioning. It takes about five minutes to complete and is usually completed with a healthcare practitioner.

Study ID: ..... Hospital: .....

Date: ..... Time: .....

Name: .....
Last First Middle Initial

Throughout our lives, most of us have times when we feel very tired or fatigued.

Have you felt unusually tired or fatigued in the last week?

Yes No

1. Please rate your fatigue (weariness, tiredness) by circling the one number that best describes your fatigue right NOW.

1	2	3	4	5	6	7	8	9	10
No Fatigue									As bad as you can imagine

2. Please rate your fatigue (weariness, tiredness) by circling the one number that best describes your USUAL level of fatigue during the past 24 hours.

1	2	3	4	5	6	7	8	9	10
No Fatigue									As bad as you can imagine

3. Please rate your fatigue (weariness, tiredness) by circling the one number that best describes your WORST level of fatigue during the past 24 hours.

1	2	3	4	5	6	7	8	9	10
No Fatigue									As bad as you can imagine

4. Circle the one number that describes how, during the past 24 hours, fatigue has interfered with your:

A. General activity.

1	2	3	4	5	6	7	8	9	10
Does not interfere									Completely interferes

B. Mood.

1	2	3	4	5	6	7	8	9	10
Does not interfere									Completely interferes

C. Walking ability.

1	2	3	4	5	6	7	8	9	10
Does not interfere									Completely interferes

D. Normal work (includes both work outside the home and daily chores).

1	2	3	4	5	6	7	8	9	10
Does not interfere									Completely interferes

E. Relations with other people.

1 2 3 4 5 6 7 8 9 10

Does not interfere — Completely interferes

F. Enjoyment of life.

1 2 3 4 5 6 7 8 9 10

Does not interfere — Completely interferes

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Useful links

www.brainstrust.org.uk/brain-tumour-support/resources/downloads/

www.cochrane.org/CD011376/GYNAECA_interventions-management-fatigue-adults-primary-brain-tumour

www.cancerresearchuk.org/about-cancer/coping/physically/fatigue/what-is-cancer-fatigue

https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/tiredness

My notes

My notes

DO NOT
DISTURB

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the brain cancer people

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