

SECTION 1.

Impacts of Brain Cancer



Making sense of the impacts of your diagnosis and treatment is an important part of living with brain cancer.

Understanding how brain cancer affects you on a day-to-day basis will help you get the support and assistance you need to manage and make plans. This section talks about some of the biggest challenges faced by people with brain cancer: fatigue or extreme tiredness, memory and concentration problems and changes to the way you think and behave. The information will help you understand what situations trigger your fatigue, or make you think less clearly. This section also offers strategies and ideas to help you manage these impacts in your daily life.

A PERSONAL EXPERIENCE

My biggest challenge...

“My biggest challenge was thinking that when I finished treatment I would be better and I would go back to normal. But that doesn’t happen... I had awful side effects and still have some now. So for me, a challenge has been learning what is normal with my body now. I just wish somebody had told me that was how it was going to be.”

– PAUL



It's normal...

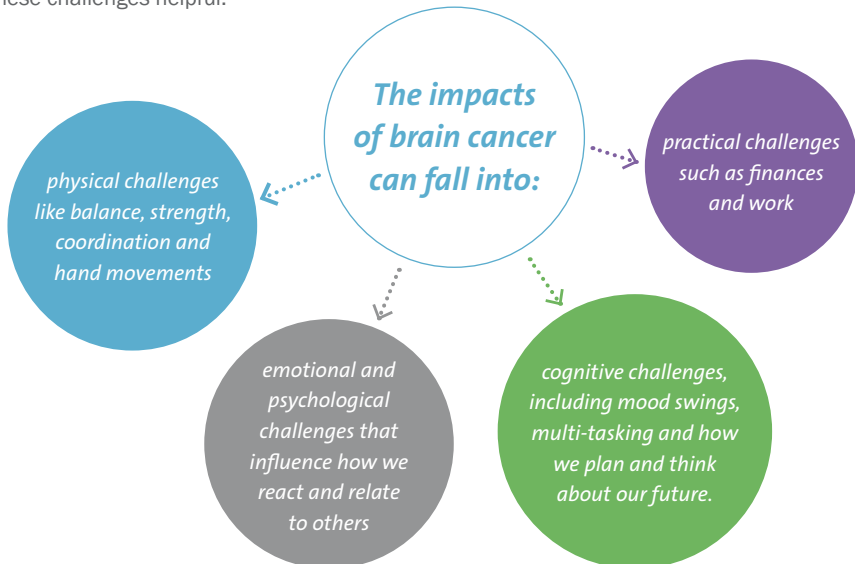
The first thing to say is that your experience is absolutely normal and has been experienced by many others before you. The impacts of brain cancer, especially some that are a lower grade, can be hidden and aren't as noticeable to other people in your life. This can feel frustrating, because people

may not understand how it impacts on your day to day life. For example, it might be harder to concentrate in busy environments or to remember important events.

Some things stay the same...

While many parts of your life will change after a brain cancer diagnosis, it's important to check in with yourself and recognise the things in your life that haven't changed. Building on the aspects of your life that feel less changed will help you to find ways to manage current and future challenges. Sometimes you can do this on your own, but many people find talking to others about these challenges helpful.

Many people living with brain cancer experience similar problems. Fatigue, memory and concentration problems are some of the most common. Because the brain is complex, the impacts of brain cancer will depend on where the tumour is located and what role this area has in controlling brain function.



It's challenging...

As much as there are common challenges, every person diagnosed will find that brain cancer impacts them in different ways. Understanding how cancer impacts your life will help you work out what you need, prioritise those needs, and take steps

to lessen the impact. If you notice changes in the way you do or think about things, it's important that you tell those close to you and look for help to understand the changes. This can help you find ways to improve these symptoms or develop new ways to manage things.

Cautionary tale about 'Dr Google'

There's a lot of information available on the internet but this can be scary, unhelpful and not specific to your situation. Consider what you are looking at and try to limit yourself to recommended websites. Importantly, you need reliable, accurate and balanced information to build your knowledge and understanding, not frightening information that will cause distress.

"I think the one thing I was told when I went through treatments was 'don't Google' because there's too much information out there online that is not accurate. If you do decide to Google, use a list of websites that are recommended. You don't look at everything!"

– DAVID



Recommended Resources

CANCER COUNCIL:

The Cancer Council website is a reliable source of information on brain cancer.

www.cancer.org.au/about-cancer/types-of-cancer/brain-cancer.html

The Cancer Council also has a booklet, Understanding Brain Tumours – A guide for people with brain or spinal cord tumours, their families and friends. It is available online or you can call 13 11 20 to order a free copy.

www.cancer.org.au/about-cancer

BRAIN TUMOUR ALLIANCE AUSTRALIA (BTAA):

BTAA is a national brain tumour patient and caregiver organisation in Australia.

Their website has resources and links to useful websites, fact sheets and booklets.

www.btaa.org.au/

THE BRAIN TUMOUR CHARITY:

This is a UK-based charity dedicated to providing support and information for people with brain tumours, their families and friends.

www.thebraintumourcharity.org/

CURE BRAIN CANCER FOUNDATION:

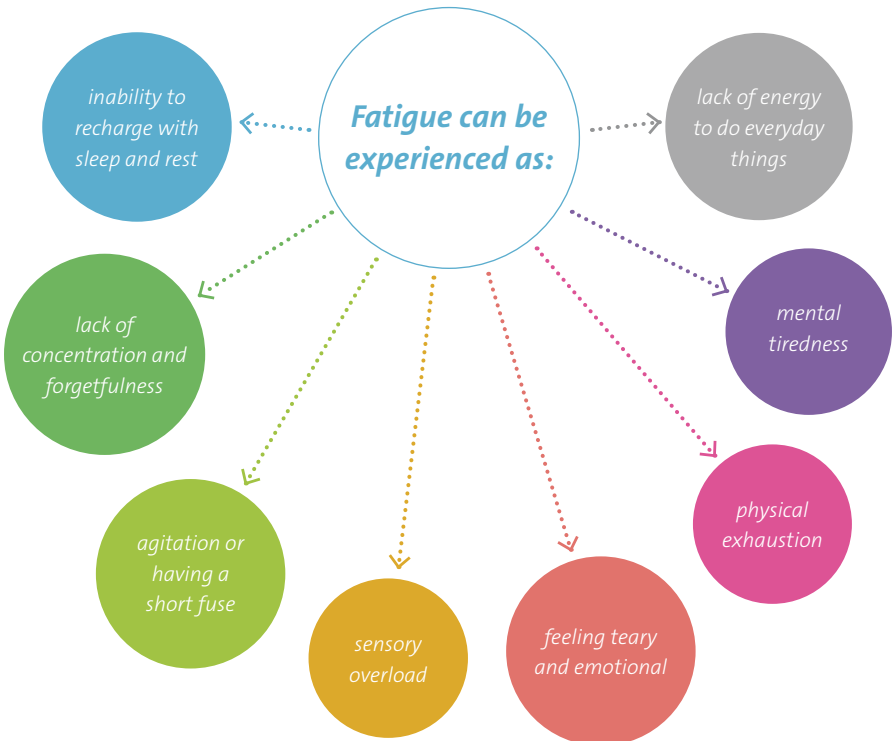
This foundation is dedicated to improving brain cancer research, advocacy and awareness in Australia.

www.curebraincancer.org.au/

Fatigue

Fatigue is the most common symptom experienced by people with brain cancer. Whether people are diagnosed with a low grade glioma or a higher grade glioma, fatigue remains a challenge to manage as part of everyday life. Like an invisible weight, fatigue is often unnoticed or misunderstood by others around you, but can have a significant impact on your quality of life.

Fatigue in brain cancer is not caused by one thing; there is often a range of factors involved. It can be a life-long symptom of having brain cancer. It may improve or worsen at different times, often depending on what is going on in your life.



What makes brains with cancer tired

The fact that you have brain cancer means that thinking, moving, planning, laughing and talking may all take extra concentration, effort and energy...

This can mean you get tired more quickly than before your diagnosis. Treatments like radiotherapy, chemotherapy, surgery, steroids or anti-seizure medications can also cause fatigue. If you experience seizures, that can cause tiredness as well.

Feeling overwhelmed by busy environments, loud music, or children playing noisily can be a type of sensory overload. People with brain cancer experience cognitive fatigue and sensory overload because they find it difficult to filter out the unimportant stuff.

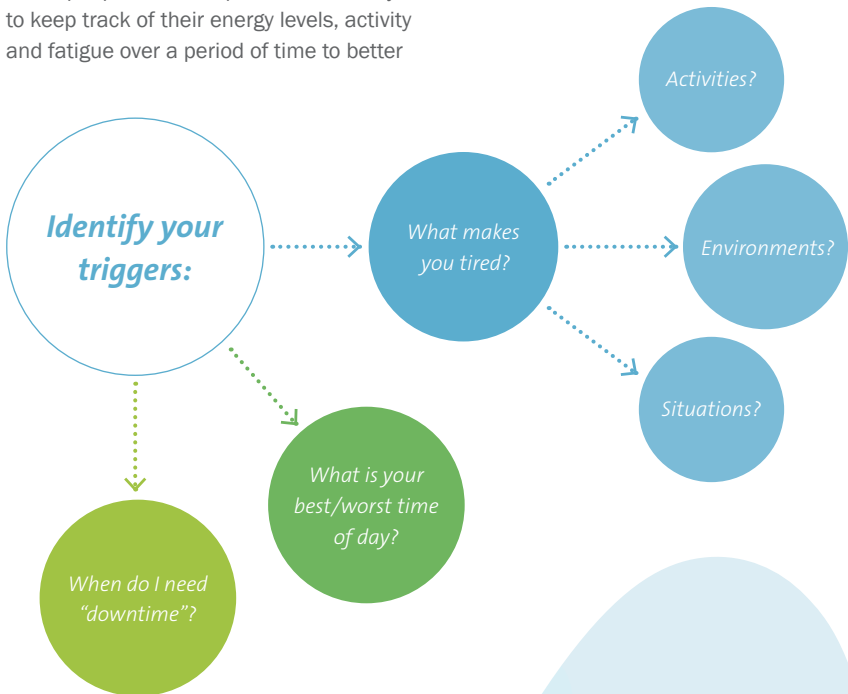
Then there is stress and worry. Feeling stressed, worried or sad about what is going on in your life (brain cancer related or not) can result in poor sleep, not looking after yourself and feeling emotionally exhausted.



What are your triggers?

It is important to work out what situations trigger your fatigue. Working out your main triggers will help you plan how best to manage. Try to think about the activities and situations that leave you drained. Some people find it helpful to use a diary to keep track of their energy levels, activity and fatigue over a period of time to better

understand what is happening for them. When you have a better understanding of your fatigue triggers, you can put some strategies in place to better manage.



What can help?

Looking after yourself by getting enough sleep, eating well, drinking enough water and doing a bit of exercise can be a great start to managing fatigue better. Here is a list of tips recommended by brain cancer health professionals to help manage fatigue.

Top tips for managing fatigue

PACE YOURSELF

- Balance your activity with rest periods to avoid exhaustion. Don't use exhaustion as a guide for when to stop; rest before you start to feel tired.
- Plan tasks and activities for the times of day when your energy levels feel best.
- Limit screen time, such as watching television and using computers, and break up long periods of sitting.
- When you are feeling tired, sit when possible (for example, when preparing dinner).

SLEEP ROUTINE

- Have a regular sleep routine. Sleep is essential to maintain your energy levels throughout the day. Relax before going to bed; if you have trouble relaxing, try guided relaxation or meditation (e.g. Insight Timer – a free meditation phone app).
- Nap or rest without distractions (such as TV) during the day. Limit your nap time to 60 minutes and avoid napping close to your intended bedtime. Naps late in the day can make it harder to fall or stay asleep at night.

- Can-Sleep is a useful self-help booklet developed by the Peter MacCallum Cancer Centre: <https://www.petermac.org/services/cancer-information-resources/can-sleep>

GETTING SOME EXERCISE

- Exercise can help improve your mental, physical and emotional health, as well as manage you fatigue. Be careful to avoid overdoing your activities as this will worsen fatigue. See Exercising after treatment on page 49.
- Go outside. A lack of fresh air and sunlight can contribute to fatigue and irritability.

FUELLING YOUR BODY

- Eat a well-balanced diet to keep your strength and energy up. See Nutrition Advice on page 46.
- Drink enough water (around 8 glasses of fluid per day). Staying hydrated will help lessen fatigue and help your body deal with medications and treatments.

RELAX AND UNWIND

- Take the time to completely unwind, relax, and let go. If you have trouble relaxing, try guided relaxation techniques such as deep breathing, meditation, yoga and Tai Chi.
- Try to negotiate some 'downtime' in the day where you (and the family) just do quieter activities. No visitors, no screens, no loud play.

GET ORGANISED

- Start by making a simple plan. You'll find setting new goals easier once you show yourself you can reach the things you wanted to achieve. See Making a Plan on page 111.
- Keep lists. Make sure that your tasks are written down so you don't forget anything important. It might help to list the most important tasks at the top of the list. Remind yourself that most people never get to the bottom of their to-do lists.
- Gradually build up a daily routine that incorporates fatigue management strategies that work for you.
- Accept your choices on activities. It's a real balance; sometimes deciding you want to go to that concert or spend longer time with friends will mean you are more tired. Try to build in a quieter recovery day following a big event.

ASK FOR HELP

- Sometimes people don't know you need help or how best to help... tell others how they can help you.
- Tell your family and friends about your fatigue. Often those closest to you can help spot fatigue. Listen to them and trust their judgement.
- Accepting help from friends and family can be an important part of managing better on a day-to-day basis. Don't be afraid to accept or ask for help.
- Getting some professional input can be useful. Rehabilitation and fatigue management programs can teach you skills and strategies to manage your fatigue. Refer to the 'Practical support' section, page 73.

Recommended Resources

THE BRAIN TUMOUR CHARITY: UNDERSTANDING BRAIN TUMOURS

This can be viewed as a website or printed fact sheet. It provides information on brain cancer related fatigue and strategies for coping with this fatigue.

<https://www.thebraintumourcharity.org/living-with-a-brain-tumour/side-effects/fatigue-and-brain-tumours/>

CANCER COUNCIL: COPING WITH CANCER FATIGUE

This is a two page fact sheet providing some tips on managing cancer-related fatigue.

<https://www.cancerciv.org.au/living-with-cancer/common-side-effects/fatigue>

NATIONAL BRAIN TUMOUR SOCIETY: BRAIN TUMOURS AND FATIGUE

This fact sheet discusses the causes of brain cancer fatigue and strategies that can help manage this fatigue.

<https://braintumor.org/brain-tumor-information/>

BRAINSTRUST: MY FATIGUE BOOK

This 60-page downloadable book explains brain cancer related fatigue and has strategies to self-manage this fatigue.

<https://brainstrust.org.uk/brain-tumour-support/quality-of-life/living-well-with-a-brain-tumour/fatigue/>

Fatigue strategies checklist

SELF-CARE

- drinking water
- eating regular meals
- exercising to build your energy levels
- getting a good sleep overnight.

SORT YOUR ROUTINE

- start your day with 3-5 key tasks
- schedule downtime during the day
- keep a checklist of daily reminders. Put it in a convenient location where you look at it frequently (or keep it on your phone).
- change tasks every 30-45 minutes e.g. physical tasks vs thinking tasks, chores vs fun activities.

PRIORITISE YOUR ACTIVITIES

- do important stuff at your best time of day
- spend your energy wisely on activities of greatest value
- identify what restores energy.

ORGANISE THE TEAM

- ask for and accept help
- tell others how they can support you
- adopt a champion – see page 61



Thinking and brain cancer

The brain is a very complex organ, performing complex tasks every day. It does things we don't even notice. Subtle things like having poor sleep, or significant things such as a brain cancer diagnosis, can impact the way we think, understand and act.

This section talks about some common impacts on thinking and behaviour people may experience. Remember that not everyone will experience these changes, and if they do, they may not be long-lasting. If you find some of the things discussed in this section apply to you, read page 89 for how to access rehabilitation and discuss your concerns with your treating team.

What is cognition?

Cognition refers to the mental skills or functions that the brain is responsible for, including: thinking, understanding, learning, remembering, concentrating, problem-solving, planning, judging and decision making.

BRAIN CANCER AND COGNITIVE IMPAIRMENT

Brain cancer can affect the way the brain works and can result in difficulties with cognition. This is referred to as 'cognitive impairment'.

Not everyone with brain cancer will experience changes in their cognition or thinking. If you do experience changes, often only some — not all — mental skills are affected. The types of changes and their severity depend on various factors, including the location of the tumour.



What cognitive changes might I experience?¹

- **Attention and concentration.**
It might be harder to:
 - concentrate for long periods of time
 - keep track of multiple tasks or conversations at once
 - block out distractions around you.
- **Speed of thinking:** the speed at which the brain can take in, process and respond to information can be slower. You might take longer to:
 - complete tasks, work through problems and make a decision
 - react to something.
- **Memory and new learning:** people tend to experience difficulty with their 'short-term' memory rather than long-term or old memories. It might be harder to:
 - remember new information such as recent conversations or events
 - take in new information or learn new things.
- **Executive function:** the 'higher-level' mental skills we use for more complex tasks that take more mental effort, such as work and study. Executive functions include reasoning, planning and problem solving. You might have difficulty:
 - planning ahead and organising yourself
 - reasoning through a problem or decision
 - thinking of a new idea or way to approach a task/problem.
- **Communication skills:** the ability to understand and use spoken language as well as reading, writing and numbers. Damage to certain areas of the brain can also result in difficulty understanding and producing speech (referred to as 'dysphasia' or 'aphasia'). You might find it harder to:
 - express your thoughts, for example forgetting, mispronouncing or using the wrong words
 - understand what others say
 - read information
 - use an appropriate tone of voice
 - pick up on body language and social cues.
- **Visual spatial and perceptual skills:** the brain's ability to make sense of what the eyes see and the location of objects. It might be harder to:
 - recognize objects and put things together
 - judge distances.

Behaviour change

Some people can also experience changes in their behaviour. Like cognitive changes, changes in behaviour can depend on various factors including the location of the tumour and personal traits. Not everyone will experience changes in their behaviour.

What behaviour changes might I experience?

- Difficulty shifting ideas and doing things a different or new way.
- Being self-centred and finding it hard to see things from others' perspectives.
- Finding it harder to learn from previous experience.
- Low frustration tolerance; feeling more irritable and agitated.
- Difficulty coping with small changes in routine.
- Loss of confidence and difficulty communicating socially.
- Difficulty controlling emotions; for example, you might cry more easily.
- Acting on a thought or idea without thinking it through; for example, rushing into a task without considering the risks or saying a hurtful comment without considering the impact on someone.
- Reduced initiation: it can be harder to start tasks/activities. The 'get up and go' part of the brain may not work as effectively. This is not laziness or a lack of motivation.
- Reduced insight: due to the damage to the brain, you may not be aware of how your cognition or behaviour has been affected.

What can help?

Getting some advice on what to expect and what is common in your situation is a good place to start. Speak with your treating specialist, your GP or cancer care coordinator. Sometimes people find it helpful to have a review and assessment of their thinking skills with a health professional such as a neuropsychologist. A neuropsychologist can be a bit difficult

and costly to access, but many public and private health services can refer you for an assessment. Accessing a rehabilitation program where you can work with a speech pathologist or occupational therapist could also help you develop strategies to manage changes to your thinking skills. The section on Practical Support in this booklet (page 73) talks about how to access rehabilitation.

Recommended Resources

AUSTRALIAN PSYCHOLOGICAL SOCIETY: FIND A PSYCHOLOGIST

This is a searchable website to locate a neuropsychologist in your area.

<https://www.psychology.org.au/Find-a-Psychologist>

THE BRAIN CANCER GROUP

This website has links to some great factsheets about changes in thinking and behaviour from the NSW Cancer Institute.

<https://braincancergroup.com.au/resources-research/patient-carer-info>

THE BRAIN TUMOUR CHARITY: COGNITION AND BRAIN TUMOURS

<https://www.thebraintumourcharity.org/living-with-a-brain-tumour/side-effects/cognition-and-brain-tumours/>

THE BRAIN TUMOUR CHARITY: MEMORY DIFFICULTIES AND BRAIN TUMOURS

<https://www.thebraintumourcharity.org/living-with-a-brain-tumour/side-effects/memory-difficulties-and-brain-tumours/>

THE BRAIN TUMOUR CHARITY: PERSONALITY CHANGES AND BRAIN TUMOURS

<https://www.thebraintumourcharity.org/living-with-a-brain-tumour/side-effects/personality-changes/>

CANCER COUNCIL: UNDERSTANDING CHANGES IN THINKING AND MEMORY

<https://www.cancervic.org.au/about/publications/newsletters/information-support-news-health-professionals/understanding-changes-in-thinking-memory.html>

FAMILY, FRIENDS AND CARERS INFORMATION:

Impacts of brain cancer

A brain cancer diagnosis has a large impact, affecting not only the person with cancer, but also their family and friends. In this resource, carer means someone who helps, supports or looks after a family member or friend with brain cancer. As part of the support team, it is important for you to know the impacts of brain cancer, the support available to you and most importantly, to remember to look after yourself.

Impacts of brain cancer

The impacts of brain cancer largely depend on the tumour location, size and how fast the tumour grows. Cancer treatments can also cause symptoms and side effects. As well as physical symptoms such as tiredness, the person's behaviour and personality may be affected. This can include changes in their mood and thinking. Because brain cancer affects people in different ways, the person you are caring for may have many or no symptoms.

The types of symptoms and side effects that may occur from brain cancer and its treatment include:

- physical symptoms: headaches, fits (seizures), tiredness, nausea (feeling sick), changed appetite, bowel problems and muscle weakness or paralysis. The person's vision, hearing, taste and smell can be affected.^{2,3}

- thinking and behaviour symptoms: personality changes, mood swings, withdrawal, confusion, impaired judgement, memory loss, difficulty multi-tasking and planning, socially inappropriate behaviour and trouble speaking, reading, and/or writing²
- emotional symptoms: coping with cancer can be stressful and scary. The person may become more or less emotional than usual. Common emotions people experience include: sadness, depression, anxiety, irritability and anger.²

The side effects may resolve gradually as the person recovers from treatment, or they can be permanent. It can help to keep a diary of these changes or behaviours so you can see if they improve, stay the same or get worse. If you are worried, speak to your doctor or health professional for advice. It can also help to write down any questions before you see a health professional.

Communication problems

Symptoms and side effects can lead to communication difficulties. The old ways you had of talking, understanding and responding to the person affected by cancer may be different now. This can be frustrating and challenging for both of you. Here are some tips that may help you.²⁻³

- Talk in short and simple sentences, but be careful to not 'talk down' or treat the person like a child. Check to see if the person has fully understood you. When needed, say things differently or simplify your point.
- Talk about one thing at a time and avoid distractions, such as other conversations or busy environments. For example, turn off the TV when you're having a conversation.
- Fatigue and memory loss can make it difficult to think about lots of things at once. A calm, soothing environment may help.
- Be a good listener. Strong communication depends on good listening. Check if you understand the person correctly by repeating things back to them. Don't interrupt as this can affect what the person is trying to tell you.
- Keep instructions very simple and get into the habit of writing them down. This allows the person to read what you said again later.
- Go slow. Allow extra time for the person to take in, think and respond to the information you provide. Avoid rushing the person and finishing their sentences.
- Encourage talking and use nonverbal cues. When you can see each other's faces it makes understanding easier. Maintaining eye contact can also help create a positive and comfortable environment.
- Acknowledge difficulties if the person is getting upset or frustrated. Keep your voice calm and lowered where possible. If the person continues to get upset or angry, walk away instead of continuing to argue.

It may be useful to share these communication tips with friends and family so they can adjust the way they interact. Explain any changes in the person's function or behaviour to them so they know from the beginning. You may also pick up things that work and do not work through keeping notes and discussing ideas with the person's medical team. Some people withdraw or become socially isolated during and after treatment. Try keep them as involved as you can, even if you just tell them about things that are going on.

Recommended Resources

CANCER COUNCIL: UNDERSTANDING BRAIN TUMOURS

This booklet (available online or hardcopy) provides in-depth information on the symptoms a person with brain cancer may experience.

www.cancercouncil.com.au/brain-cancer/symptoms/



Building THE **Bridge**
to Life with Brain Cancer

Phone 03 9496 3315

Email buildingthebridge@austin.org.au

145 Studley Road, Heidelberg VIC 3084

www.buildingthebridge.com.au

www.onjcancercentre.org

www.austin.org.au