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Living Well With A Brain Tumour

PATIENT GUIDE



Living Well With A Brain Tumour



Taking steps to ensure you live well with a brain tumour

When you are diagnosed with a brain tumour it is a big shock and it can feel that your life has been interrupted or put on hold, but if you are living with or beyond your brain tumour you are a survivor. This can mean having an inoperable brain tumour or living a brain tumour-free life having experienced surgery and/or other treatments.

Emotionally, the changes you experience may be difficult to cope with. You may find that your self-esteem and your relationships, especially with those close to you, are affected. Brain Tumour Support NZ wants to ensure that you are aware of the help that is available to you here in New Zealand. Your wellbeing will be greater, and there will be less need for you to call upon these services, if you get the support that is relevant to your particular needs, specifically those that promote a healthy lifestyle and independence.

Some people experience changes in how their mind and body works as a result of a brain tumour, or treatment for a tumour. You or your family members may notice changes in your speech, personality, memory, movement, balance and coordination – there is help available to you.

The brain can sometimes heal itself after treatment, but this can be a slow process. Some patients require some form of rehabilitation to help restore their abilities or manage changes. The type of treatment you may have depends on your needs and your choices, and sometimes on whether the treatment is available at a hospital close to where you live.



Recommendations from international guidelines

- Ongoing health and social care support needs should be discussed both with you and your family, whānau, and carers (as appropriate). Complex care support needs, such as psychological, cognitive, physical, spiritual, cultural and emotional needs should be taken into account.
- Enough time should be set aside to discuss your ongoing health and social care support needs.
- Information and support should be given empathetically in suitable formats and at appropriate times throughout your care pathway.
- Clinical results (scans, blood and other tests) should be provided and clearly explained to you as soon as possible.
- Neuro-rehabilitation assessment and options should be given throughout the care pathway. Potential neuro-rehabilitation needs include:
 - Audiology
 - Neuropsychology
 - Occupational therapy
 - Physical therapy
 - Orthoptics (visual support)
 - Speech and language therapy.
- Appointments for assessments should be arranged so that timing and frequency fit your neuro-rehabilitation goals (such as returning to work).



Rehabilitation services explained

Audiology

Audiologists assess and manage hearing and listening disorders and help to rehabilitate people with hearing loss. They test a person's hearing and measure the type and degree of any hearing loss. If you notice a change in your hearing or you have any concerns about your hearing, talk to your GP so that they can refer you to the appropriate person.

Cognitive rehabilitation

Your memory, language skills, concentration, or planning and problem-solving skills (executive function) may be affected. A neuropsychologist, speech pathologist or occupational therapist can help improve these cognitive skills using memory activities, speech therapy, diaries and language puzzles.

Exercise

A physiotherapist or an exercise physiologist can give you advice on how to exercise safely and stimulate parts of your body to improve circulation and reduce swelling.

Vision

If you notice a change in your vision or you have any concerns about your eyesight, talk to your GP or eye health professional.

Occupational therapy

Some people find the tumour or its treatment affects their ability to perform everyday personal activities (e.g. showering, dressing, preparing a meal). An occupational therapist can help you to return to the activities that are important to you. A range of strategies and aids can help you manage fatigue and improve or maintain your independence.

Social workers

There will be a social worker at your hospital. They are there to help you with a number of difficulties. For example, if you are worried about how you will manage when you get home and what help might be available; if financing your care needs is worrying you; or if you would like to talk to someone about how your brain tumour might affect you and your family.

If you require any of these services please talk to your GP or hospital doctors who will be able to refer you to the appropriate specialist(s).



Managing seizures

A brain tumour or treatment for a brain tumour can sometimes bring on seizures. Seizures (fits or convulsions) are disruptions to the normal patterns of electrical impulses in the brain.

Seizures can usually be prevented with anticonvulsant medicines (also called anti-epileptic or anti-seizure medicines). You can also reduce your seizure risk by making sure you don't get too tired or fatigued.

Generalised seizures

These types of seizures typically affect the whole body. The most common type is called a tonic-clonic seizure (previously known as a grand mal seizure). A seizure often starts with a sudden cry, followed by the person falling down and losing consciousness. The person's muscles may twitch violently, and their breathing may be shallow for up to two minutes. They may lose bladder and bowel control and bite their tongue.

Partial seizures

These affect one part of the body, such as an arm or leg. Symptoms include twitching, jerking, tingling or numbness, and altered sensations (hallucinations), such as changed vision or hearing, strange tastes or smells, or a feeling of déjà vu. Partial seizures may cause a brief loss of consciousness or changes in memory loss just before, during and after the seizure.

Anticonvulsant medicines

There are many types of anticonvulsant drugs which are used to prevent seizures. You may require blood tests while you are taking anticonvulsants. This is to check whether the dose is effective and how your liver is coping with the medicine.

Side effects of anticonvulsant drugs vary, but they may include tiredness, gum problems, shakes (tremors), nausea, vomiting, weight changes, depression, irritability and aggression. If you are allergic to the medicine, you may get a rash. Talk to your GP or hospital doctor if you have any skin changes or other side effects. Your doctor can adjust the dose or try another anticonvulsant. It is advisable not to stop taking the medicine or change the dose without your doctor's advice.



For further information about managing seizures, consult your doctor and visit epilepsy.org.nz

Driving

It is illegal to drive while impaired in New Zealand. Brain tumour symptoms (such as seizures), treatment side effects and certain medicines (such as anticonvulsants and some pain medicines) can affect your vision, mobility, coordination, perception and judgement, making it unsafe for you to drive. The New Zealand Transport Agency (NZTA) provides guidelines which help assess a brain tumour patient's fitness to drive.

When you are first diagnosed with a brain tumour, it is likely that your doctor will advise you not to drive for a period of time. The time that you have off driving will depend on a number of factors, including: your tumour type and grade; the location of your tumour; whether or not you have experienced seizures; the treatment you have had

for your tumour; and any ongoing symptoms. For example, if you have been diagnosed with a high grade (grade 3 or 4) glioma, or a metastatic (secondary) brain tumour, NZTA guidelines state that driving should cease for a minimum period of three years following treatment, depending on circumstances.

Before you start driving again, you must always check with your doctor. Laws in New Zealand require drivers to tell the NZTA about any permanent or long-term illness or injury that is likely to affect their ability to drive. Your doctor can advise you if you should report your condition or if there are any temporary restrictions. The NZTA may request information from your doctor to decide if you are medically fit to drive. This may include an assessment report from an approved occupational therapist.



Returning to work

It can be hard to predict how well you will recover from treatment for a brain tumour, and when and whether you will be able to return to work. This will also depend on the type of work you do.

Some people find it hard to concentrate or make decisions after treatment. At first, it may not be safe to operate heavy machinery or take on a lot of responsibility. Your doctor will be able to advise you about whether returning to work is safe or possible. They can also give your employer information about whether you could return to work with altered duties or on a part-time basis.

Talk to your employer about adjusting your duties or working part-time until you have recovered. In some cases, it won't be possible to return to your former role. This can be hard to accept, and it may help to talk to a Cancer Society of New Zealand trained counsellor.



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Counselling and support

Counselling can mean different things to different people. It can be anything from a cup of tea and a chat with a friend, to professional counselling. The aim of professional counselling is to improve your quality of life, and to help you to cope with the emotional effects of living with a brain tumour. Counselling can help you improve and ease any tensions within your family and whānau, and to find strategies for coping. It is also a place to go and 'off-load' without upsetting your family and whānau.

A counsellor will:

- Listen to what you are saying.
- Help you to sort through your feelings.
- Provide you with some insight as to how you are thinking and feeling.

- Help you to express your emotions in your own way.
- Help you to work out your own solutions to problems.
- Help you to adjust to your own particular situation.

A free professional counselling service is offered by the Cancer Society of New Zealand for both patients and their family or whānau. To find a counsellor talk to your local Cancer Society office or ring the Cancer Society Information Helpline on 0800 CANCER (226 237).

Work and Income benefits

If your health affects your ability to work there are a number of benefits that you may be entitled to. This can be a difficult system to navigate and sometimes it is easier to speak to someone from the Work and Income general enquiries team on 0800 559 009 as they will be able to provide you with advice that directly relates to your situation. Your GP will be able to provide you with any medical certificates that you require to support your application.

Travel insurance

All travel insurance policies exclude pre-existing conditions and you need to be aware of this before you travel overseas. This means air fare cancellation and any costs related to your cancer while travelling abroad are not recoverable unless you've declared your pre-existing conditions and paid any additional premium required by your insurer.

When applying for travel insurance, be sure to answer all of the health questions carefully and fully disclose your pre-existing conditions. The insurer will make an assessment based on your current health and treatment status. You may find that some companies offer full cover at an additional premium. Others may decline full cover but offer partial cover with special acceptance terms or higher excess levels.

New Zealand has reciprocal healthcare arrangements with Australia and the United Kingdom. This means treatment of any immediate or necessary health issue should be covered while you are in these countries. This does not extend to treatment in private hospitals or treatment that you have specifically travelled to Australia or the UK for. Medical repatriation is also not covered.¹

If you're looking for travel insurance it is worth contacting the New Zealand Cancer Society Information Helpline as they may know of some individual insurers who may be able to help you – 0800 CANCER (226 237).



KiwiSaver

You may be able to withdraw your KiwiSaver savings early under certain circumstances. Please talk to your KiwiSaver provider or visit the website for further details: ird.govt.nz/kiwisaver/kiwisaver-individuals/getting-my-kiwisaver-funds-early/getting-my-kiwisaver-for-serious-illness

Diet

While the overall benefits of following a healthy diet have always been stressed by healthcare professionals, there is an ongoing discussion and a need for further research about the potential role of diet and nutrition in the treatment of brain tumours.

A healthy diet is associated with numerous general health benefits, including reducing the risk of other medical conditions such as diabetes, heart disease as well as some types of cancer. Adopting a healthier diet after being diagnosed with a brain tumour could benefit you in the following ways:

- Keeping up your strength and energy
- Maintaining your weight and your body's store of nutrients
- Lowering your risk of infection
- Aiding the healing and recovery process.

For more information on the foods that make up a healthy diet please visit cancer.org.nz/cancer/reducing-your-cancer-risk/healthy-kai/



Can diet help treat my brain tumour?

There has been growing interest in the possible effectiveness of specific diet regimes and micronutrients for the treatment of brain tumours and their related symptoms. Most notably, an increasing number of people affected by brain tumours are trying the ketogenic diet alongside more conventional forms of treatment. However, as yet there is a lack of scientific evidence for its effectiveness in the treatment of brain tumours or brain tumour-related epilepsy. Despite this lack of evidence, some people affected by brain tumours choose to follow the diet. It is important that if you wish to follow a ketogenic or other alternative diet, you should talk to your doctor or dietitian. This is because they may affect your treatment and interfere with observations of your condition by your medical team.

Exercise

There is evidence to show that exercise can help your body to work at its best when you are living with a brain tumour². Exercise can improve strength, fitness, mood and general well-being. However, 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, your treatment can cause side effects such

as fatigue, dizziness, weakness and lack of balance, making the situation worse.

Long-term use of steroids, which may be given to alleviate symptoms may cause side effects such as muscle wasting. So exercise may be particularly difficult for some people living with a brain tumour.

Equally though, exercise may bring the greatest benefit. The most important thing is to do what works for you. Here are some tips which you might find useful:

- Walking can be an easy activity to build into your daily routine. Others might choose yoga, pilates, Tai Chi, cycling, swimming or dance classes like Zumba.
- If balance is a problem, exercises can be done whilst sitting down. Or practice standing while lightly holding on to a kitchen bench or heavy piece of furniture. Let go of it intermittently but stay close enough so you can grab onto 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 heels repeatedly, rather than to practice balancing on one leg. Exercise in short sessions for three to five minutes a few times a day, rather than longer single sessions.
- Add gentle stretching exercises to your regimen.
- Yoga and pilates are 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 in a while, set a realistic goal of five minutes, gradually increasing 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, brighten your mood and improve your balance and coordination.



Complementary therapies

Complementary therapies are therapies that are used alongside the conventional medical treatments prescribed by your doctor. They may help you to feel better and improve your quality of life. They may also help you to cope better with some symptoms caused by the brain tumour or the side effects caused by some of the treatments.

A good complementary therapist won't claim that the therapy will cure your brain tumour and they will always encourage you to discuss any complementary therapies with your doctors or GP.

There are many different types of complementary therapies including the following examples:

Exercise can improve strength, fitness, mood and general well-being. However, exercise isn't always straightforward when you have a brain tumour.



- Aromatherapy
- Acupuncture
- Herbal medicine
- Massage therapy
- Visualisation
- Yoga

Many healthcare professionals are supportive of people with brain tumours using complementary therapies although some healthcare professionals are reluctant and this is usually because these therapies have not been scientifically tested in the same way as conventional treatments.

Many complementary therapies have been evaluated and are safe and effective to use together with conventional brain tumour treatment and medicine. However, some complementary therapies, such as herbal medicines or supplements, can affect the way conventional treatments work, even stopping them from working altogether or causing side effects.

Some people think natural products are safe, but this isn't always true. Some products may affect how well other medicines work in your body. Always tell your GP and hospital doctors if you are using complementary medicines.

Alternative therapies

Alternative therapies include unproven treatments that are promoted as a substitute for conventional medical treatments. Many of these therapies do not have the support of health professionals because there is insufficient proof that they work. Organisations including the Cancer Society or the UK's National Institute for Health Care and Excellence (NICE) do not recommend using alternative therapies in place of hospital treatments. It is often tempting for brain tumour patients to seek alternative therapies to enhance the treatment plan prescribed by their doctors or if they are not confident that conventional treatments will work. If you are thinking about using alternative therapy we recommend you talk about it with your doctor.



The Cancer Society of New Zealand

The Cancer Society of New Zealand provides people living with cancer a wealth of information and support. For more information about how they can support you and your family or whānau please call into your local Cancer Society office or call 0800 CANCER (0800 226 237).

What questions could I ask my healthcare team?

Below are a number of questions which you can ask your doctor or specialist. You may not want or need to ask all of the questions on this list. You may want to ask questions of your own. It is helpful to bring a list of questions to your appointment and write down or record the answers. If you don't understand the answer, ask the doctor to explain. Remember, it's ok to ask the same question more than once and there really is no such thing as a silly question.

- For how many years going forward should I expect to have scans?
- Are there any long term consequences that I should be mindful of?
- Who supports me now I am at this point?
- Which doctor should I contact if I need assistance, my GP or my oncologist?
- Can I keep doing my chosen sport or activity?



- What do I do if I am concerned in any way?
- What financial support is available to me?
- What help is there for carers?
- How can I contact other patients who have the same tumour as me?
- Can you give me more information about any future seizures I can expect?
- I want to make the best of this phase. Is there anything or anyone who can help me with this?
- When can I drive again?
- Should I change my diet?
- Should I stop eating sugar?
- Should I be taking health supplements?
- What are my next steps?

For more information about how we can help you, please visit braintumoursupport.org.nz



Last words...

Reading all this information may feel overwhelming, but there is help and support available to you.

Brain Tumour Support NZ can help you to find what you need for your particular circumstances and to ensure that you can continue living your life in the best way possible. Please don't hesitate to get in touch with us and we will try our very best to help you.



Sources



brainstrust

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Disclaimer

This patient guide reflects current recommendations from international clinical guidelines for the management of primary adult brain tumours. It is not intended to take the place of medical advice. A patient's GP or specialist may provide them with new or different information which is more appropriate to their needs.

New Zealand does not have its own set of clinical practice guidelines for the management of brain tumours. New Zealand doctors will typically refer to international guidelines, from organisations such as: the UK's National Institute for Health and Care Excellence (NICE); the European Society of Medical Oncology (ESMO); the European Association of Neuro-Oncology (EANO); Cancer Council Australia; and the USA's National Comprehensive Care Network (NCCN). Links to these international guidelines can be found in our Online Resources directory.

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