

He waka
eke noa

**brain
tumour
supportNZ**
In it together

1

Introduction

PATIENT GUIDE

Introduction



What are the Brain Tumour Support NZ Patient Guides?

The purpose of these guides is to enable you to feel more in control – whether you are the person diagnosed with a brain tumour, or a carer, whānau or family member, or a person who is important to them.

This can be a very scary time for everyone involved and it may be difficult to know what you should ask and to whom you should turn to for help and information. To support you in these moments, these guides are intended to help you understand what to expect along the way. We want to ensure that you are aware of:

- What is likely to happen at different points along the pathway, although this will be different for each person.
- What the optimum standard of care is (according to international guidelines) at each point of the pathway.
- What else Brain Tumour Support NZ thinks you should expect – to help you make the most of the resources around you (over and above the optimum standard).
- Suggested questions for you to ask your healthcare professionals (but only if you want to).
- What Brain Tumour Support NZ can do to help you.

These guides are offered to support adults diagnosed with a brain tumour, although some of the questions and suggestions may be helpful for children with a brain tumour and for their families and whānau.



How might I use these guides?

It is important for you to remember that these guides map out a whole patient pathway, but this might not be your pathway.

As there are over 130 different types of brain tumours, the experience of living with a brain tumour can be very different for each person. Even brain tumours of the same type and grade may differ according to their genetic makeup and their location in the brain. So it's important that you only refer to the guides that are relevant to your diagnosis and to remember that the pathway may not always be linear. You can refer to these guides at any time so that you know what you might expect according to the optimum standard.

In some parts of the guides we refer to a “holistic approach” to your treatment plan. This recognises that people with a brain tumour diagnosis face special emotional, physical and practical challenges. The best care for a person with a brain tumour is provided by doctors and other health professionals, with different areas of expertise, working together as a team (called “multidisciplinary care”).

When assessing your treatment options, your doctors will consider a multitude of factors besides your tumour type and grade. These will include your: age; medical history; comorbidities (other health conditions you might have); family circumstances; and your general fitness and well-being. If you have had surgery they will take into account the extent of resection and your performance status (how you are coping) after the surgery. Every patient is different – it is important that any proposed treatment plan is tailored to your personal goals and preferences.



If you are worried about any of the care you receive you can share your concerns with your specialist doctors or your GP. Please bear in mind that a GP may only see one person in their professional life who has been diagnosed with a brain tumour. The suggested lists of questions do not cover every topic but are intended as prompts if you should need them. When asking questions make sure that you are willing to hear the answers, as once you have been given knowledge this can't be undone. Only ask the questions for which you want to know the answers.

Throughout the guides we refer to recommended international guidelines. New Zealand does not have its own set of clinical practice guidelines for the management of brain tumours. New Zealand specialists will typically refer to international guidelines produced by 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.

How are the Patient Guides organised?

There are seven guides each covering a different part of the pathway. You may choose to refer to just one or many of them. Remember that not all guides may be relevant to you and some may never be. The six guides are:

1. Introduction
2. Diagnosis
3. Knowing my tumour type
4. Treatment
5. Follow-up
6. Living well with a brain tumour
7. Palliative Care

You can download these guides at braintumoursupport.org.nz/brain-tumour-patient-guides

At the end of each guide you will find links to organisations or publications from which the content has been sourced. These publications are also listed on our website at braintumoursupport.org.nz/resources



Support available

Hearing that you have a brain tumour is challenging and at times it may feel like you are alone. You are not. Many of us here at Brain Tumour Support NZ have experienced what it is like to be diagnosed and to live with a brain tumour, or have a family member who has had a brain tumour. We want you to know that we are all 'in it together/he waka eke noa'.

We can help you to feel less afraid, less alone and more empowered – we understand. Below are some examples of the help available to you from Brain Tumour Support NZ. Don't hesitate to get in touch with us and talk to people who have been where you are now.

What can Brain Tumour Support NZ do to help?

For more information about any of these resources, visit our website, email us, or find us on social media:

-  braintumoursupport.org.nz
-  hi@braintumoursupport.org.nz
-  [braintumoursupportNZ](https://www.facebook.com/braintumoursupportNZ)
-  [@btsupportnz](https://twitter.com/btsupportnz)
-  [braintumoursupportNZ](https://www.instagram.com/braintumoursupportNZ)
-  [braintumoursupportnz](https://www.linkedin.com/company/braintumoursupportnz)

Resources to keep you informed and help you feel more in control

braintumoursupport.org.nz

The main website for Brain Tumour Support NZ contains lots of information and advice for people diagnosed with a brain tumour in New Zealand. Here you will find:

- The Brain Tumour Support NZ patient guides – read online or download the PDFs.
- Support Friends – a free service which puts you in touch with one-to-one support within New Zealand.
- Information – about signs and symptoms, brain tumour types, molecular markers, and more.
- NZ Directory – a list of useful contacts for practical help and support.
- Jargon Buster – a glossary of medical terminology to help explain commonly used technical terms.
- Online Resources – a website directory of useful links from New Zealand and overseas.
- Brain Box – order a free care and information package.
- Online Support – how to join our Facebook groups or monthly online support groups.

The Brain Tumour Support NZ Patient Guides

These guides have been produced to help you know what to expect at each stage along your treatment pathway, from diagnosis to life after treatment. There are seven easy-to-understand guides, to be used individually or as a complete set.

They have been designed to read online or you can print them out and take them along to your doctor's appointments. Towards the end of each guide there is a list of possible questions that you might want to ask, and space to write down the answers.

The information in the guides has been sourced from international guidelines and has been reviewed by New Zealand specialists who are experienced in treating brain tumours to ensure that it is appropriate for New Zealand patients.

Visit braintumoursupport.org.nz/brain-tumour-patient-guides to read our guides.

“It's so good to have some information that I can understand so that it can help me to make decisions.”

Support Friends NZ

It is very common for patients diagnosed with a brain tumour to experience feelings of fear and loneliness. You

may find it helpful to talk to one of our Support Friends. These are people who can relate to your situation and have either been diagnosed with a brain tumour or have experience of caring for someone with a brain tumour. Support Friends NZ is a free support service for people diagnosed with a brain tumour, or for a member of their family or whānau. It doesn't matter where you live in New Zealand, all you need is access to a phone or the internet.

The Brain Tumour Support NZ official Facebook page

[facebook.com/
braintumoursupportNZ](https://facebook.com/braintumoursupportNZ)

This is the official Facebook page for Brain Tumour Support NZ where we post news, information, fundraising events, awareness-raising opportunities, and much more. You can find out about our latest activities and how you can get involved as a volunteer or supporter.

Brain Tumour Support NZ Facebook group for patients

[facebook.com/groups/
BTSNZpatients](https://facebook.com/groups/BTSNZpatients)

Facebook users can join this closed support group where New Zealand brain tumour patients hang out to swap experiences, share information or just chat. This is a community of people who are in the same boat as you and everyone very much wants to support each other. The group is private, so prospective members must be approved and conversations are seen by members only.

Brain Tumour Support NZ Facebook group for carers

[facebook.com/groups/
BTSNZcaregivers](https://facebook.com/groups/BTSNZcaregivers)

This is a Facebook support group for New Zealand carers of people with a brain tumour. Looking after a brain tumour patient can be a very hard and lonely job at times. This group is a forum where carers can ask questions, offer advice or just have a general chat and a good laugh away from those that they look after. Like the patient support group, the carers group will be closed and monitored for privacy.

Jargon buster

The medical jargon and terminology written in your records or when doctors and healthcare professionals are talking to you can be very complex and difficult to understand. You may choose to look at your records (and you are entitled to) and need some help understanding them. Our website contains a glossary that explains many of these terms in easy-to-understand language.

New Zealand directory

This is where you will find the contact details for a list of agencies or organisations providing helpful services, support and resources for New Zealand brain tumour patients. The topics include:

- Counselling and guidance
- Financial advice
- Practical solutions



- Support programmes for carers and patients
- Connection with an online brain tumour community
- Resources to help you feel less alone

International resources and downloads

There is a huge amount of information on the internet about brain tumours. However unfortunately not all of the information you access is factually correct or reliable. Due to advances in research, information about brain tumours and treatments is constantly being updated. On our website you will find a list of online resources, from New Zealand and overseas, which we have verified as being authentic, accurate and reputable. Many of these are in PDF format and are free to download.

For more information about
any of these resources, visit
braintumoursupport.org.nz





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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); 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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Get in touch for more information



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