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Follow-Up

PATIENT GUIDE





Scope of this Patient Guide

This Patient Guide covers the follow-up treatment of tumours that behave as:

- Low Grade Gliomas (grades 1 and 2 in the World Health Organization (WHO) classification)¹
- High Grade Gliomas (WHO grades 3 and 4) including glioblastoma multiforme (GBM)
- Meningiomas

There are over 130 different types of primary brain and central nervous system tumours, as defined by the World Health Organisation (WHO) classification system. It is beyond the scope of this guide to cover the follow-up treatment for all of these tumour types as well as metastatic (secondary) brain tumours.



What happens?

Following diagnosis, many people have treatment, whilst for some people the most appropriate care is active monitoring (also called watchful waiting). When you move into this follow-up phase, you will most likely have regular clinical reviews, normally an MRI scan followed by an appointment with your specialist. The exact follow-up will be based on your specific type of tumour, and how it is likely to behave.

You may expect life to return to how it was before you were diagnosed with a brain tumour, but it takes time to recover from treatment and come to terms with the diagnosis. Many people find that although life never returns to the way it was before, they start living a 'new normal' – a way of life that is normal to you now. For some people the tumour is gone or it is stable and likely to remain that way. For others, it's a process of coming to terms with a longer term condition and the reality that your tumour is not going away and may undergo changes.

For some, this can open up new opportunities. Others, however, describe this time as 'falling off the edge', and feeling isolated or unsupported. It's probably a bit of both. Whichever it is, it's important to know how you, and those around you, can feel resourced, supported and prepared. Brain Tumour Support NZ offers a range of support services to help you adjust to your new normal and help you through the difficult times. Please see our website braintumoursupport.org.nz for more information.

What is the optimum standard of care according to international guidelines?

The optimum standard of care states the minimum level of care we should expect. Sometimes, for a variety of reasons, our health service may not be able to meet the optimum standards. As not all hospitals offer the same range of services, your follow-up treatment may differ according to where you live or you may be referred to another hospital for treatment. The standard of care you should expect is:

- Routine imaging.
- Regular clinical reviews to assess changes in your physical, psychological and cognitive wellbeing.



- Ready access to assessment and rehabilitation services for problems such as epilepsy (seizures), headaches, and speech or visual problems.
- Ready access to specialist neuropsychology and neuropsychiatry services.
- Ready access to physical or occupational therapy services.
- Access to specialist equipment that would assist rehabilitation as necessary.
- Clear information on who to contact and how, if you are concerned about your condition.
- Follow-up as close to home as possible.

Recommendations from the international clinical guidelines

- The timing of regular clinical reviews will be based on any brain tumour that is left after treatment, life expectancy, your preferences, previous treatments, available treatment options and the specific type of tumour.
- MRI scans may be used as part of regular clinical review. Additional scans using advanced MRI techniques may be used if the findings from standard imaging are unclear.
- An MRI 24–48 hours after surgery helps detect changes that are due to the surgery, such as bleeding. These scans can be kept as a record so that, months or years later, the abnormal appearance caused by surgery will not be mistaken for signs that the tumour has changed to become higher grade (more rapidly growing).
- Another follow-up MRI is usually done 6–12 weeks after a person has received radiotherapy. Note that it can sometimes be difficult to determine if any changes in brain appearance on the scan are caused by treatment (including damage caused by radiation) or by the tumour growing and worsening.



- Scanning for a glioma will then be done at regular intervals depending on the type of glioma. Table 1 (see page 6) indicates possible scan intervals for different grades of glioma according to the latest NICE guidelines.
- Scanning for a meningioma will be done at regular intervals depending on the type of meningioma. Table 2 (see page 7) indicates possible scan intervals for different grades of meningioma according to the latest NICE guidelines.
- You will be made aware that imaging can be difficult to interpret and results can sometimes be uncertain. Having routine imaging and waiting for results may cause anxiety. Sometimes this can outweigh the benefits of having a scan.
- A clinical review with appropriate imaging will be arranged for patients who develop new or changing neurological symptoms or signs at any time.
- Health and social care professionals will address additional complex needs during or after treatment and throughout follow-up. These include:
 - » changes to cognitive functioning
 - » fatigue
 - » loss of personal identity
 - » loss of independence
 - » maintaining a sense of hope
 - » potential for change in personal relationships



- » the challenges of living with uncertainty
- » the impact of brain-tumour-associated epilepsy (seizures) on wellbeing.
- Your risk of developing late side effects of treatment will be assessed when you finish treatment. Such side effects can develop months or years after treatment and may include cataracts, cavernoma, cognitive decline, epilepsy, hearing loss, hypopituitarism, infertility, neuropathy, radionecrosis, secondary tumours and stroke. Advice will be given to you on how to monitor for late-onset side effects based on individual needs.

Table 1: Possible regular clinical review schedule for people with glioma depending on grade of tumour

	Years after end of treatment					
	0–1	1–2	2–3	3–4	5–10	>10 (for the rest of life)
Grade 1	Scan at 12 months, then: <ul style="list-style-type: none"> • consider discharge if no tumour visible on imaging unless completely resected pilocytic astrocytoma • consider ongoing imaging at increasing intervals for 15 years for completely resected pilocytic astrocytoma • consider if ongoing imaging is needed at a rate of once every 1 to 3 years for the rest of the person’s life if the tumour is visible on imaging. 					
Grade 2 1p/19q non-codeleted, IDH mutated	Scan at 3 months, then every 6 months	Annually	Every 1 to 2 years	Consider ongoing imaging every 1 to 2 years		
Grade 2 1p/19q codeleted						
Grade 3 1p/19q codeleted						
Grade 2 IDH wild type	Every 3 to 6 months	Every 6 to 12 months	Annually	Consider ongoing imaging every 1 to 2 years		
Grade 3 1p/19q non-codeleted						
Grade 4 (glioblastoma)						

Table reprinted from NICE guideline: [nice.org.uk/guidance/ng99](https://www.nice.org.uk/guidance/ng99)

Scanning for a glioma will be done at regular intervals depending on the type of glioma.



Table 2: Possible regular clinical review schedule for people with meningioma depending on grade of tumour

	Years after end of treatment										
	0 to 1	1 to 2	2 to 3	3 to 4	4 to 5	5 to 6	6 to 7	7 to 8	8 to 9	>9 (for the rest of life)	
Grade 1: no residual tumour*	Scan at 3 months	Annually		Once every 2 years							Consider discharge
Grade 1: residual tumour*	Scan at 3 months	Annually				Once every 2 years				Consider discharge	
Grade 1: after radiotherapy	Scan 6 months after radiotherapy	Annually		Once every 2 years							Consider discharge
Grade 2	Scan at 3 months then 6 to 12 months later	Annually				Once every 2 years				Consider discharge	
Grade 3	Every 3 to 6 months		Every 6 to 12 months			Annually					
Asymptomatic incidental meningioma	Scan at 12 months. If no change consider discharge or scan at 5 years.										

*The presence of any residual tumour can only be established after the first scan at 3 months.

Table reprinted from NICE guideline: [nice.org.uk/guidance/ng99](https://www.nice.org.uk/guidance/ng99)



What does Brain Tumour Support NZ think I should expect?

- Regular, ongoing holistic support, which encompasses physical, emotional, spiritual, cultural and cognitive needs.
- If you are concerned your brain tumour might be returning, an urgent appointment with your specialist.
- Information on how to access assessment from allied health professionals such as: counsellors, physical and occupational therapists, psychologists, social workers, speech therapists and others.
- Your primary care provider (such as your GP) to signpost supportive resources to you, including support organisations such as the Cancer Society and Brain Tumour Support NZ.
- Support for your carer and close persons.
- Timely assessments so that you can be proactive, not reactive, based around functional and neurological assessments.

What questions could I ask?

Before asking questions, think carefully about how much you truly want to know. Once you have knowledge of your diagnosis and prognosis, it cannot be undone. You may find it helpful to talk about your situation with family and friends before asking any questions.

You may have heard your doctors use some of the terms mentioned in this patient guide when referring to your specific tumour type. If you're finding this overwhelming or difficult to understand, you're not alone. Speak to someone from your healthcare team or key worker, usually a clinical nurse specialist (CNS), cancer nurse co-ordinator (CNC) or community oncology nurse if you want someone to explain them to you.



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.

- What follow-up care can I expect?
- When will my next scan be?
- How long after I have had my scan will I get the results?
- Who will look after me when I'm discharged back home?
- Which doctor should I see, and how often?
- Are there any post-treatment symptoms I should be aware of?
- What do I do about symptoms that worry me?
- What can be done to relieve pain, fatigue or other problems after treatment?
- How long will it take me to feel more like myself?
- Is there anything I can do to stop the tumour coming back?
- Who can I get in touch with if I have any questions?
- When can I go back to work?
- When can I drive again?



Additional questions you may want to ask

- What are the chances that the tumour will come back?
- If it does return, what are my options?
- What will happen with the tumour that couldn't be removed?
- Will it grow? If so, when is this likely to happen?
- What treatment will be likely, or might be possible, in the future?

If you don't understand the answer, ask the doctor to explain.



Sources



brainstrust

Patient Guide (accessed August 2019)

brainstrust.org.uk/brain-tumour-support/navigating-your-pathway/patient-guides

National Institute for Health Care and Excellence (NICE)

NICE Guideline: Brain tumours (primary) and brain metastases in adults (July 2018)

nice.org.uk/guidance/ng99

Improving Outcomes for People with Brain and Other CNS Tumours (June 2006)

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European Society for Medical Oncology (ESMO)

ESMO Clinical Practice Guidelines: High-Grade Malignant Glioma

esmo.org/Guidelines/Neuro-Oncology/High-Grade-Malignant-Glioma

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Clinical Practice Guidelines for the management of adult gliomas: astrocytomas and oligodendrogliomas (2009)

cancer.org.au/content/pdf/HealthProfessionals/ClinicalGuidelines/Clinical%20Practice%20Guidelines%20Adult%20GliomasAugust%202009.pdf

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Cancer Council Australia

Understanding Brain Tumours (April 2018)

cancer.org.au/content/about_cancer/ebooks/cancertypes/Understanding_Brain_tumours_booklet_April_2018.pdf

Cancer Society of New Zealand

Brain Tumour Information Pack (2019)

References



1. World Health Organisation (WHO) 2016 Classification of Tumours of the Central Nervous System

braintumor.org/wp-content/assets/WHO-Central-Nervous-System-Tumor-Classification.pdf







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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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