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brain tumour support NZ

In it together

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Treatment

PATIENT GUIDE

Treatment

Scope of this Patient Guide

This Patient Guide covers 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 brain and central nervous system tumours, as defined by the WHO classification system. It is beyond the scope of this guide to cover all of these tumour types. Some common tumour types which are not covered in this guide include:

- Ependymomas
- Pituitary tumours
- Schwannomas
- Central Nervous System (CNS) Lymphomas
- Spinal cord tumours
- Metastatic (secondary) brain tumours

Information about these and other types of brain tumours can be found on the Brain Tumour Support NZ website at **braintumoursupport.org.nz**

See page 15 for references

What happens?

After your tumour has been diagnosed, your doctors will discuss what treatment options are most appropriate for you, taking into account your tumour's size, location, cell type, grade, and any molecular or genetic information. Treatment may include periods of observation (surveillance), surgery, radiotherapy, chemotherapy, and combinations of all or some of these treatments in different ways. Your lead consultant or specialist will discuss the options with you; this may be a neurosurgeon, oncologist or neurologist.

Your options will have been discussed with a team of doctors at a multidisciplinary meeting (MDM)[2]. This is an internal hospital meeting where a range of health professionals such as surgeons, oncologists, radiologists and clinical nurse specialists meet together to discuss your case.

What is the optimum standard of care for low grade gliomas (WHO Grades 1 and 2) according to international guidelines?

Common types of low-grade gliomas include:

- Astrocytoma, IDH-mutant (Grade 2)
- Oligodendroglioma, IDH-mutant and 1p/19q codeleted (Grade 2)

For more information on tumour types, visit **braintumoursupport.org.nz/braintumour-types** and **braintumoursupport.org.nz/online-resources**

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 standards. As not all hospitals offer the same range of services, your treatment plan may differ according to where you live or you may be referred to another hospital for treatment.

This is the optimum standard of care:

- 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").

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- The neuroscience team, which will typically include a neurosurgeon and a neurologist, will be responsible for deciding your surgery and adjuvant therapy (treatment after surgery in order to lower risk of tumour recurrence). The oncology team will be responsible for your care post-surgery, including chemotherapy, radiotherapy and coordination of supportive care. To ensure continuity and alignment between teams, your doctors will discuss your recommended treatment pathway in a multidisciplinary meeting (MDM)[2].
- The MDM members may include the following people:
  - » a neurologist
  - » a radiologist
  - » a neurosurgeon
  - » a pathologist or neuropathologist
  - » radiation and medical oncologists
  - » a clinical nurse specialist, oncology (cancer) nurse or cancer nurse coordinator
  - » a palliative care specialist
  - » one or more allied health or psychosocial professionals
- No treatment decisions can be made without your agreement. Your proposed course of treatment will be communicated to you in a clear and concise way so that you can make a fully informed decision (this is called "informed consent").
- You will have the opportunity to ask questions of your doctor, including the objectives of the proposed treatment and any possible risks or side effects you may experience as a result of the treatment.
- Either watchful waiting (sometimes called active surveillance or active monitoring) or early surgical intervention.
- 31 day indicator – patients with a confirmed cancer diagnosis receive their first cancer treatment (or other management) within 31 days of a decision to treat.

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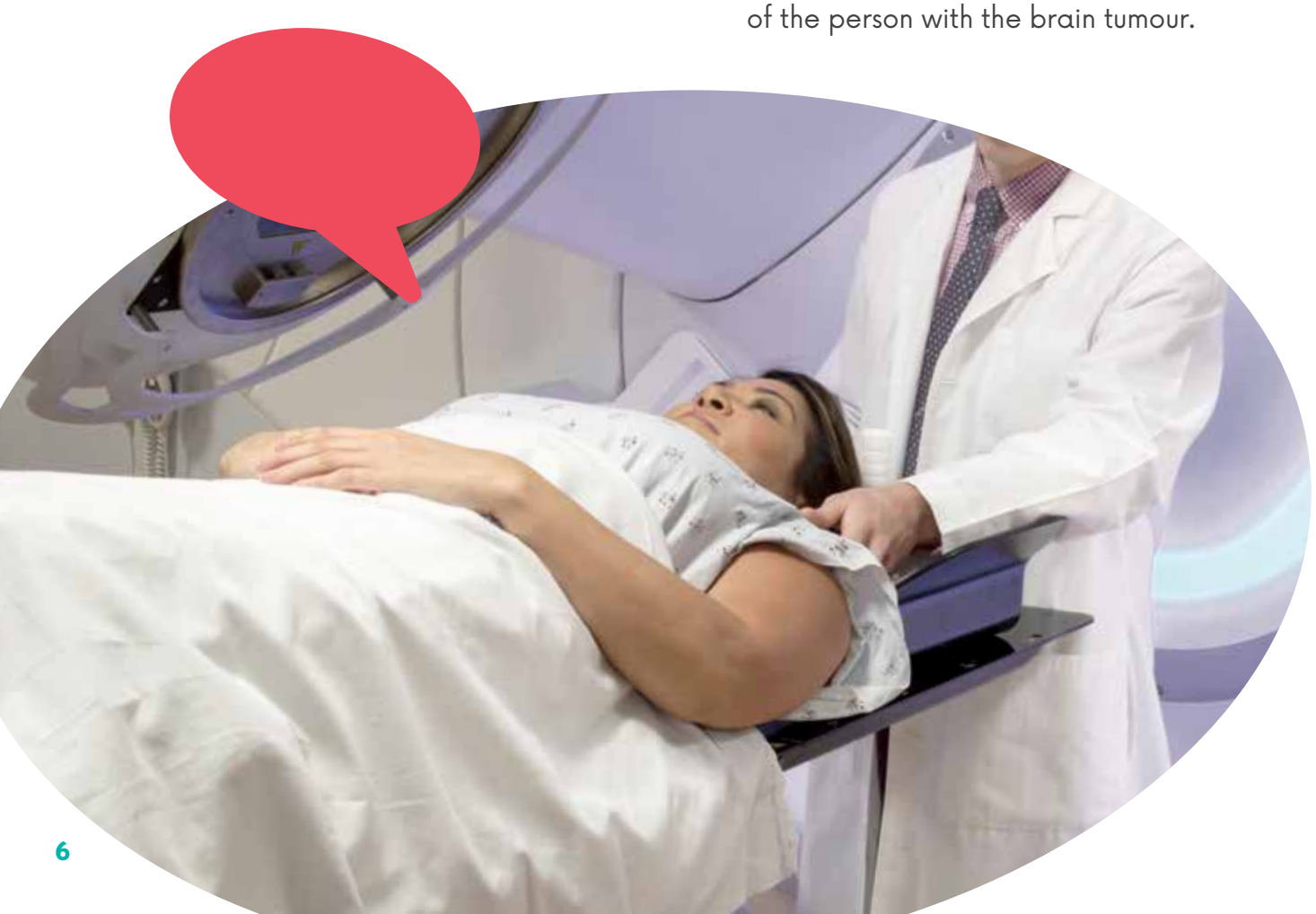
- 62 day indicator – patients referred urgently with a high suspicion of cancer receive their first treatment (or other management) within 62 days of the referral being received by the hospital.[3]
- Possible radiotherapy.
- Possible chemotherapy.
- To be told about any relevant clinical trials.
- The opportunity to discuss potential preservation of fertility where treatment may have an impact on your fertility.

Recommendations for low grade gliomas based on international guidelines

- Surgery to remove all or part of your tumour may be considered as part of initial management. This is different to a biopsy, which takes a small amount of tissue for histological and molecular diagnosis. This diagnosis will provide information on how your tumour is likely to behave and how it is likely to respond to treatment.
- Surgery to remove the tumour, also called a resection, aims to remove all or as much of the tumour as safely possible. Before your operation, your neurosurgeon will meet with you to discuss the extent of your surgery. How much tumour to remove is a balance of potential benefits versus the risk of disability.
- An awake craniotomy may be considered to preserve neurological function. This will be discussed with you. An awake craniotomy is when neurosurgery happens with the person awake for all or part of the surgery. This is a preferred technique for operations to remove tumours close to, or involving, functionally important areas of the brain. The overall aim is to minimise the risks of such operations. The risks of awake surgery for a brain tumour are the same as those for conventional surgery, but there is also a small risk of seizures during surgery that might in rare circumstances require conversion to general anaesthetic. Some people may find the thought of an awake craniotomy very stressful. Your suitability for this surgery will be discussed with you. Other specialists, such as neuropsychologists and speech and language therapists, will be involved with your care before, during and after awake craniotomy.

- If it isn't possible or not considered appropriate to get a diagnosis of a low-grade tumour via biopsy, then active monitoring (sometimes called watchful waiting) will be followed. This means regular scanning of the tumour at set intervals. If the tumour shows progression (so it looks like it is growing or the cells are changing), your doctors will discuss whether surgery to remove some or all of the tumour, or biopsy, is now appropriate. This will then be discussed with you.
- After surgery, if you are 40 or over or you have a tumour over 2cm left behind, you may be offered a course of radiotherapy, followed by up to six cycles of chemotherapy. Active monitoring may be considered for patients aged under 40 with an IDH-mutated low-grade glioma and no residual tumour on postoperative MRI.
- If you have not had radiotherapy before, and if the disease is progressive or you have seizures that don't respond to medication, then radiotherapy may be considered, followed by 6 cycles of procarbazine, lomustine and vincristine (PCV) chemotherapy. Your doctors will agree the order of chemotherapy and radiotherapy with you.
- The prognosis for people with histologically confirmed IDH-wildtype grade 2 glioma may be similar to that of people with glioblastoma if other molecular features are consistent with glioblastoma, and this should be taken into account when thinking about management options.

Note that every case is reviewed individually and there are many more options for treatment based on the tumour type, grade, and age and health of the person with the brain tumour.



What is the optimum standard of care for high grade gliomas (WHO Grades 3 and 4) according to international guidelines?

Examples of high-grade gliomas include:

- Astrocytoma, IDH-mutant (Grade 3 or 4)
- Oligodendroglioma, IDH-mutant and 1p/19q codeleted (Grade 3)
- Glioblastoma (GBM), IDH-wildtype (Grade 4)
- Diffuse midline glioma, H3K27-altered (Grade 4)

For more information on tumour types, visit **braintumoursupport.org.nz**

Optimum standard of care should include:

- A holistic approach to your treatment plan. This recognises that people with a brain tumour diagnosis face special emotional, physical, cultural 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").
- The neuroscience team, usually headed by your neurosurgeon, will be responsible for deciding on your surgery and adjuvant therapy (treatment after surgery in order to lower risk of tumour recurrence). The oncology team will be responsible for your care post-surgery, including chemotherapy, radiotherapy and coordination of supportive care. To ensure continuity and alignment between teams, your doctors will discuss your recommended treatment pathway in a multidisciplinary meeting (MDM).
- No treatment decisions can be made without your agreement. Your proposed course of treatment will be communicated to you in a clear and concise way so that you can make a fully informed decision (this is called "informed consent").
- You will have the opportunity to ask questions of your doctor, including the objectives of the proposed treatment and any possible risks or side effects you may experience as a result of the treatment.
- 31 day indicator – patients with a confirmed cancer diagnosis receive their first cancer treatment (or other management) within 31 days of a decision to treat.

- 62 day indicator – patients referred urgently with a high suspicion of cancer receive their first treatment (or other management) within 62 days of the referral being received by the hospital.[3]
- Surgery, if appropriate. This may include:
  - » Urgent surgery (i.e. emergency surgery) also called resection or debulking.
  - » Planned surgery (biopsy, partial or maximum removal).
- If, on balance, the risks of treatment outweigh the benefit or will affect quality of survival, a discussion about supportive and palliative care will take place with referral to the appropriate specialists.
- Radiotherapy may be considered following pathological diagnosis, unless a biopsy is too risky, in which case radiotherapy may be given in the absence of histology.
- Chemotherapy may be considered.
- To be told about any relevant clinical trials.
- The opportunity to discuss potential preservation of fertility where treatment may have an impact on your fertility.

Recommendations for high grade gliomas

- Technical aids to surgery and imaging may be used to help achieve surgical resection, such as Gliolan (5-ALA), ultrasound, intraoperative MRI, or diffusion tensor imaging.
- An awake craniotomy may be considered to preserve neurological function. This will be discussed with you. An awake craniotomy is when neurosurgery is done with the patient awake for all or part of the surgery. This is a preferred technique for operations to remove tumours close to, or involving, functionally important areas of the brain. The overall aim is to minimise the risks of such operations. The risks of awake surgery for a brain tumour are the same as those for conventional surgery, but there is also a small risk of seizures during surgery that might in rare circumstances require conversion to general anaesthetic. Some people may find the thought of an awake craniotomy very stressful. Your suitability for this surgery will be discussed with you. Other specialists, such as neuropsychologists and speech and language therapists, will be involved with your care before, during and after awake craniotomy.
- After surgery for grade 3 gliomas, you will be offered radiotherapy. This is usually 30 treatments five days per week over 6 weeks. This is often followed by chemotherapy. The type used depends on the molecular subtype. If the tumour has a codeletion of 1p/19q, then 4 to 6

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cycles of PCV is used. For tumours without 1p/19q codeletion, up to 6 cycles of temozolomide (an oral chemotherapy) is given. This is usually 5 days in every 28 for 6 months.

- After surgery for grade 4 gliomas (glioblastoma multiforme), patients may be offered radiotherapy with temozolomide starting at the same time, followed by 6 cycles of adjuvant temozolomide. The course of treatment depends on the fitness of the patient and the features of the tumour.
- Supportive care alone may be considered the best option for patients aged 70 or over with a grade 4 glioma, particularly if the brain tumour is causing significant disability.
- Your performance status (how well you perform activities of daily living) will be assessed throughout the period following surgery, and treatment options will be reviewed if your performance status changes.
- If you have a recurrent high grade glioma (ie. the tumour comes back after treatment) chemotherapy may be considered, using either temozolomide, PCV or other drugs.
- Your doctor may consider further surgery or radiotherapy for recurrent high-grade gliomas. They may take into account your performance status, where the tumour is, how large it is and how long it has been since your initial surgery and radiotherapy.
- Your doctor may discuss the use of Avastin (bevacizumab). Avastin is an anti-angiogenic agent which restricts tumour growth by shutting down the blood vessels which supply it with nutrients. It is registered with Medsafe to treat recurrent high grade glioma but is currently not funded by PHARMAC. The use of Avastin to treat brain tumours is not supported in all countries. For example, the UK's NICE guidelines do not currently support its use in either newly diagnosed or recurrent high grade glioma.
- You should also be advised that the current NICE guidelines do not support the use of cannabis oil, immunotherapy, ketogenic diets, metformin, statins, valganciclovir and tumour-treating-fields as treatments for high grade gliomas. These and other treatments are still considered experimental although many of them are currently undergoing clinical trials and may be recommended as treatment options in the future.
- Best supportive care alone may be considered the best option if you have a recurrent high-grade glioma and if other treatments are not likely to be of benefit, or if you would prefer this.

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

Management depends on the size, location and grade of the tumour, and the patient's fitness and symptoms.

- 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").
- Maximum removal may be appropriate.
- Radiotherapy may be considered if a biopsy shows the tumour is WHO grade 2/3, there is invasion by the tumour into adjacent brain tissue or extensive invasion of other tissue, there is a second or subsequent relapse, or there is a contra-indication to surgery.
- To be told about any relevant clinical trials.

Recommendations for meningiomas

- Management of meningiomas is based on the extent of surgery and the grade of the meningioma. Treatment may include active monitoring, further surgery and radiotherapy.
- Before a decision is made on radiotherapy, the following will be taken into account: comorbidities, life expectancy, neurological function, oedema, performance status, rate of tumour progression, size and location of tumour, surgical and radiotherapy morbidity, the patient's preferences, previous treatments.
- If your specialist thinks that radiotherapy is appropriate, the advantages and disadvantages of the treatment will be discussed with you.

What does Brain Tumour Support NZ think I should expect?

- Treatment can vary depending on the exact nature of the tumour and can vary from patient to patient.
- When assessing your treatment, your doctors should 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.
- A clear discussion about the best management for you, including the pros and cons for radiotherapy early or later, and other more experimental treatments. Every patient is different – it is important that any proposed treatment plan is tailored to your personal goals and preferences.
- You should be given a clearly defined key worker (possibly a clinical nurse specialist (CNS), oncology nurse or cancer nurse coordinator (CNC) within 1 working day (inpatient) or 5 working days (outpatient) of the multidisciplinary meeting.

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.

Questions about my treatment

- What are my brain tumour treatment choices?
- Which do you recommend for me and why? Why are these different from the optimum standard (if applicable)?
- How does that treatment work?
- If you or your family member had my type of tumour, what would you advise?
- What options are available outside my locality?
- Do I have to decide today?
- Can I wait to start treatment? What are the expected benefits of each kind of treatment?
- What can I do to prepare for treatment?
- Will I need to stay in the hospital? If so, for how long?
- What are the risks and possible side effects of each treatment? How can side effects be managed?
- How will treatment affect my normal activities?
- I might decide to seek a second opinion. What would the questions be that you would ask?
- Should I get a second opinion? Can you recommend other doctors who could give me a second opinion about my treatment options?
- Are there any complementary therapies that could help with the side effects of treatment?
- What if I choose not to have the treatment?
- If I am more interested in quality of life than length, what would you suggest?
- What are the long-term implications/ side effects of treatment?
- How many brain tumours do you treat a year?

- Would a research study (clinical trial) be appropriate for me? If it isn't, why not?
- What support services are available to me? What support services are available to my family and whānau?
- Do you have any written information that would help me understand what is happening? Can you recommend any as an addition?
- After treatment, what follow-up tests will I need, and how often will I need them?
- Would neuropsychological tests be beneficial in seeing how my brain function is affected and what could be done to improve it?
- What are my next steps?

Active-surveillance-specific questions (watchful waiting)

- What are you waiting for?
- What are the benefits of waiting? And the drawbacks?
- How often will I have scans?
- How long do I have to wait for the results?
- How long will it be until I do need treatment?
- What can I do to stay as healthy as possible?
- What are my next steps?

Surgery-specific questions

- How long will I be in hospital for?
- What will happen to my tumour after you've removed it? Can I donate it to research?
- Will you do any molecular testing on my tumour tissue?
- How will my tumour tissue be stored?
- Will my tumour tissue be available for use in clinical trials such as therapeutic vaccine trials?
- How long will it take for me to recover from the treatment?
- Is the surgeon a specialist in brain tumour surgery?
- What are the next steps?

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

Radiotherapy-specific questions

- What type of radiotherapy do you suggest?
- What will the side effects be, physical and emotional? And when will they kick in?
- Should someone come with me to radiotherapy sessions?
- Will I lose my hair?
- How long will it take for me to recover from the treatment?
- Is stereotactic radiotherapy/ radiosurgery suitable for me?
- What are the next steps?
- Where does it take place?
- Can I drive afterwards?
- Can I go to work afterwards?

Chemotherapy-specific questions

- What chemotherapy am I being offered?
- What will the side effects be, physical and emotional? When will they kick in?
- If chemotherapy is offered, can I have molecular testing to see if my tumour will respond to the treatment?
- How long will it take for me to recover from the treatment?
- What are the next steps?

Remember, it's ok to ask the same question more than once and there really is no such thing as a silly question.

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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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