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brain tumour support NZ

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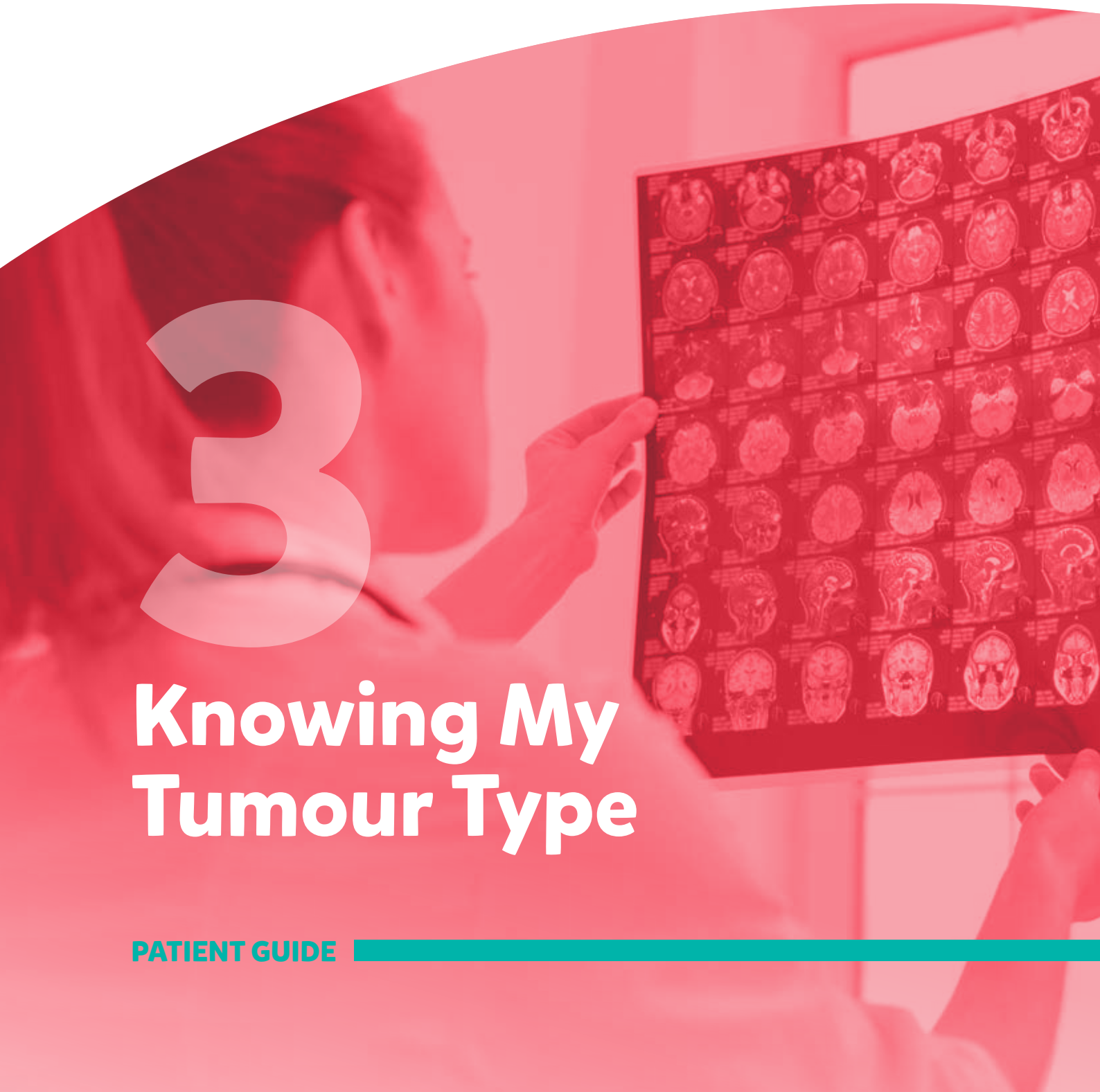

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Knowing My Tumour Type

PATIENT GUIDE

Knowing My Tumour Type

Receiving a diagnosis of a brain tumour after biopsy or resection can be an overwhelming experience.

You probably have many questions you want to ask. It's normal to feel scared, insecure, or angry when confronted with a brain tumour diagnosis. It is important to know that you are not alone. For more information, support and how to contact us visit **braintumoursupport.org.nz**

What happens?

If you have had a biopsy or resection, a specialist in interpreting the pathology of brain tissue (neuropathologist) will examine the cells in your tumour's tissue in the laboratory. The pathologist will be able to see what cell type and grade of tumour you have.

Histopathology is the study of diseased tissues at a minute (microscopic) level. For more information about a neuropathologist visit **braintumoursupport.org.nz/whos-in-your-team**

Your doctor will likely characterise your tumour as non-malignant or malignant.

Non-malignant (sometimes referred to as benign) – A non-malignant brain tumour does not contain cancer cells. It typically grows slowly with clearly defined borders and does not spread to other parts of the brain. However non-malignant tumours can still be life threatening depending on their size and location in the brain, and they have the potential to develop into higher grade tumours. WHO grade 1 and 2 brain tumours are considered non-malignant.

Malignant – A malignant brain tumour contains cancer cells. It grows more rapidly, often without clearly defined borders, and can invade surrounding brain tissue, although they rarely spread outside the brain or spine. WHO grade 3 and 4 brain tumours are considered malignant.

If your brain tumour started from the cells in your brain it is called a primary brain tumour. If your brain tumour has

been found to originate from another part of your body, it is a metastatic or secondary brain tumour. Secondary brain tumours are more common than primary brain tumours and are named by the location in which they began.

As well as histopathological assessment, your tumour specimen may have been tested for molecular markers including:

- IDH1 and IDH2 mutations.
- ATRX mutations to identify IDH mutant astrocytomas and glioblastomas (GBM).
- 1p/19q codeletion to identify oligodendrogliomas.
- histone H3.3K27M mutations in midline gliomas.
- BRAF fusion and gene mutation to identify pilocytic astrocytoma.
- High grade glioma specimens may be tested for MGMT promoter methylation to inform prognosis and guide treatment.

For more information about molecular markers visit **braintumoursupport.org.nz**

Receiving news

It is a good idea to take someone with you when you receive the results of your biopsy. A good person would be someone who can be your advocate (support person), help listen and maybe take notes. They should help you to ask the questions that are important to you and discuss the consultation with you afterwards. It can help to take the same person with you each time, as they will be able to support you when you are at home. This may include helping you to explain your diagnosis to other people that are important to you.

The result should be communicated to you face to face, sensitively and in a private space; it's okay to ask if there is somewhere more private that you can be when you are talking to a doctor or nurse at any time. If you want family, whānau or friends with you, then you should be able to have them there.

Your doctor or health professional has a legal obligation to notify the New Zealand Transport Agency (NZTA) if you are diagnosed with a brain tumour and they will advise you of any stand down period when you will not be allowed to drive. To return to driving, you may be required to perform a full assessment of driving skills with an occupational therapist trained in driving assessment.[1]

See page 7 for references

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

- All tumours diagnosed on imaging (CT or MRI scan) need to have a confirmed histopathological diagnosis, through biopsy, unless the neuroscience multidisciplinary team decides that a biopsy would be too risky or is otherwise inappropriate.
- Timely and efficient compliance with national cancer waiting time targets (histopathology results may be returned within 4 to 7 days). Some additional tests may take longer and may be sent to other hospitals for examination.
- The histopathological findings of your tumour will be discussed in a neuroscience multidisciplinary meeting (MDM[2]) and compared with images and clinical disease features. Your case will be discussed within 1 to 2 weeks after surgery. A final report is then written. This report should also be sent to your GP.

Recommendations

- Brain tumours will be reported using the latest version of the World Health Organisation (WHO) classification.
- As well as a histopathological assessment, molecular markers also referred to as biomarkers, will also be included in a diagnosis. Molecular markers are important because the information they provide can help diagnose your tumour. In certain tumours types they may also suggest how your tumour may respond to certain treatments and also provide information that can help inform your prognosis (likely outcome of your treatment).
- Genetic loss on chromosomes 1p/19q (called 1p/19q codeletion) is important in the diagnosis of oligodendrogliomas. In general, people with an oligodendroglioma that have the 1p/19 codeletion have a better response to treatment and improved prognosis than those without the codeletion.

See page 7 for references

- Mutations in the IDH gene 1 or 2 (called IDH-mutant) are hallmarks of low-grade glioma. When observed in high grade gliomas, such as glioblastoma (GBM), it suggests that the tumour has developed from a lower grade tumour. Less than 10% of individuals with adult GBM carry an IDH mutation, while around 60% of grade 3 gliomas are IDH mutated. IDH-mutated tumours are associated with a better prognosis.
- In high grade gliomas, MGMT methylation status will be evaluated to inform prognosis and guide treatment. MGMT methylated tumours respond better to alkylating agent chemotherapy than tumours with unmethylated MGMT.
- Testing for TERT mutations may also be considered in some gliomas to clarify diagnosis and inform prognosis.

For more information about molecular markers visit **braintumoursupport.org.nz**

What does Brain Tumour Support NZ think I should expect?

You should receive a diagnosis based on the pathology results within 1 working day if you are an inpatient, and 5 working days as an outpatient, AFTER the multidisciplinary meeting.

What questions should 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, whānau 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.

On the following page 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 is the tumour type?
- What grade of tumour do I have? What does this mean?
- Where is it in my brain? How will its position potentially impact on me? Does this explain my symptoms?
- Is the tumour non-malignant or malignant?
- If my tumour is non-malignant, is it life threatening?
- What caused my brain tumour?
- Are my children at risk of getting a brain tumour?
- Can you explain my pathology report (test results) to me?
- Who has reviewed my tumour sample?
- Has any molecular testing been done? If not, why not?

- Should I have this molecular testing done if it hasn't been done?
- Do I have to send my tumour tissue elsewhere in New Zealand or overseas to have the molecular testing done?
- If molecular testing has been done, does it suggest a particular course of treatment?
- If molecular testing has been done, how does it affect my prognosis?
- Do you have reading material that will help me understand my diagnosis?
- Who will be part of my health care team, and what does each member do?
- Can you explain multidisciplinary care to me?
- Can I receive copies of letters if I wish to?
- What happens next?

Once you leave the consultation, you may feel a range of strong emotions. There is a lot of information to take on board. It takes time to process this, and over the next few days, you will have lots of thoughts and questions. You may want to ask about surgery or your treatment plan, radiation therapy or therapies using medication and how to manage side effects. Write them down and have them ready to ask at your next appointment. Remember, you are not alone. For more information, support and how to contact us visit **braintumoursupport.org.nz**

Sources

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Permission

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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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