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# brain tumour supportNZ

In it together



## Diagnosis

PATIENT GUIDE

# Diagnosis



**If you have unexplained neurological symptoms or a brain tumour is suspected, perhaps following a change in your health, or, for example, a sudden onset of seizures, you should expect to have a diagnostic brain scan.**

This could be during an emergency admission to hospital or after referral to a specialist such as a neurologist. Sometimes brain tumours are found by chance when other things are being investigated.

## **How are brain tumours diagnosed? What happens?**

Brain tumours are identified using a CT or MRI scan.

**CT scan** – computerised tomography. Instead of sending out a single x-ray through the body, several beams are sent simultaneously from different angles. The computer then processes the results showing them as a 2D picture.

**MRI scan** – magnetic resonance imaging. This uses magnetic and radio waves, and dedicated equipment including a powerful computer, to create clear pictures of internal body structures.

An expert called a radiologist interprets the scans. The radiologist will be able to see if you have an abnormality, sometimes referred to as a lesion, which they may call a tumour. They will only be able to discover exactly what type of tumour it is if they take a sample during a biopsy. A biopsy is a procedure which removes cells or tissue from the tumour to provide more information. This is sometimes performed at the same time as more extensive surgery known as a resection. Resection or debulking surgery is often used to remove all or part of the tumour.

It is a good idea to take someone with you when you receive your scan result. A good person would be someone who can be your advocate (support person), can help listen and take notes, help you to ask the questions that are important

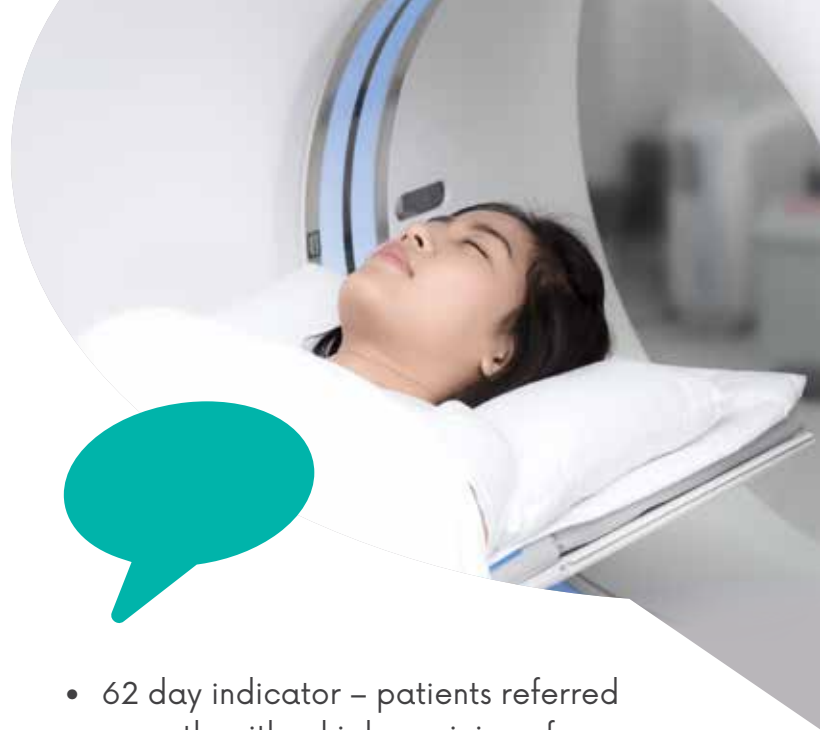
to you and discuss the consultation with you afterwards. It can help to take the same person with you each time, as they will be able to support you when you are at home. This may include helping you to explain your diagnosis, and what to expect, to other people that are important to you.

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 or friends with you, then you should be able to have them there.

## What is the optimum standard of care for all brain tumours 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 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. The minimum you should expect is:

- Timely and efficient compliance with national cancer waiting times
- 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<sup>1</sup>



- 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
- The new target covers patients referred when there is a high suspicion of cancer and the hospital doctor receiving the referral believes there is a need for an appointment within two weeks.
- Your scans and care should be discussed without delay at a neuroscience multidisciplinary meeting (MDM)<sup>2</sup>. Multidisciplinary care is a team approach to health care which includes doctors, nurses and other health professionals with skills in diagnosing and managing brain tumours. MDM members may include:
  - » a radiologist
  - » a pathologist
  - » radiation and medical oncologists
  - » a general surgeon or physician
  - » a specialist surgeon, or other surgical representative

- » a palliative care clinician
  - » a nurse – for example, a clinical nurse specialist or cancer nurse
  - » one or more allied health or psychosocial professionals
  - » Pastoral/spiritual advisor or whānau and Pacific Island health care
- During the meeting the team will review your medical history and your scan results. Everyone at the meeting is bound to keep the information confidential, just as they would in a face-to-face consultation with you.
  - MDMs are often held weekly. You should receive a diagnosis within 1 working day (if you are an inpatient) or 5 working days (as an outpatient) AFTER the MDM.
  - A written summary of your proposed management plan should be sent out within 1 working day of the MDM to your GP and your referring doctor.

- After the meeting, the person managing your care will tell you what course of action the team recommends. You will have the opportunity to ask questions and indicate any preferences you have for treatment. The final decision about your care plan is made in consultation with you.
- You should be given a clearly defined key worker (possibly a clinical nurse specialist (CNS), cancer nurse co-ordinator (CNC) or community oncology nurse within 1 working day (inpatient) or 5 working days (outpatient) of the MDM meeting.
- You should have face-to-face communication with healthcare professionals to discuss your care at critical points in your care pathway.
- You should be made aware that your health data is recorded and used.
- You should be given the opportunity to have a permanent record.
- Your psychological, cultural and social well-being should be considered.
- You should have ready access to specialist care services as appropriate, such as a clinical psychologist, social worker or other psychosocial services.
- You should have ready access to a neurosurgical biopsy or resection service, if your clinicians think this is appropriate.
- You should be given clear, accurate and relevant information throughout the course of your illness.



## Recommendations

- You should be offered standard structural magnetic resonance imaging (MRI) as the initial diagnostic test, unless MRI is not possible. A structural MRI is a non-invasive way of examining the structure (anatomy) and nature (pathology) of the brain.
- Advanced MRI techniques, such as MR perfusion may be used to assess whether a tumour that looks like a low-grade tumour on a standard structural MRI is changing to a high-grade tumour.
- CT imaging may be considered for meningioma to see if bone is involved.
- Imaging other than brain imaging might be done if it is suspected that the lesion might be a brain metastasis from cancer somewhere else in your body. This may change treatment options.
- If a brain metastasis is found, then your case will be discussed at the tumour site speciality multidisciplinary team meeting, and a biopsy will be recommended. If there is no other safe place to biopsy, then you will be referred to the oncology multidisciplinary team to discuss suitability for a biopsy.

## What does Brain Tumour Support NZ think I should expect?

- Scan results to be delivered in two weeks. It depends on when the scans are done in relation to the next multidisciplinary meeting (MDM).
- The opportunity to explore options and ask questions with your doctors or key worker. You may need to discuss options on more than one occasion, and at different times, during active monitoring and treatment periods. It's ok to ask the same questions more than once and there really is no such thing as a silly question.
- Be provided with information that is appropriate in terms of language and culture.
- Be informed of what type of tests may be carried out and what will happen during diagnostic procedures.
- Be given clear, accurate and relevant information throughout the course of your illness.
- A written personalised care plan about how your treatment and care should be carried out.





- Be provided with clear, high-quality written information in a variety of formats to support you and your relatives and carers.
- Access to a holistic needs assessment, to monitor your support needs. This will include matters that involve physical, social, emotional and spiritual/cultural needs and can relate to things outside of your illness. You should subsequently be referred to relevant services to help address these needs. This may include local support groups and services such as Brain Tumour Support NZ.
- The opportunity to request a copy of your scans and medical record, if you would like them. Your hospital will explain the process; this service is free. It is your data, and you should feel confident and exercise your right to obtain copies of your scans and medical records.
- An assessment of rehabilitation needs, if appropriate.
- Details of who you can contact out-of-hours if you have any concerns, or in the event of an emergency.

## What questions could I ask?

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 have other questions of your own. It is helpful to bring the 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 is no such thing as a silly question.

- Based on the scans, do you have an idea of the type of tumour?
- Is it a primary or secondary (metastatic) tumour?
- If I have cancer in another part of my body, is this tumour related to that?
- What do we do next? Do I need more tests? Do I need to see any specialists?
- Will I have a biopsy to determine what the tumour is?
- If you're going to operate, are you planning to take out all or part of my tumour as well as doing a biopsy? If so, how much do you plan to take out?
- What are the risks in removing this tumour?
- Who will be part of my healthcare team, and what do they do?
- Who will coordinate my overall treatment and overall care?
- Can I still drive?



- Has my case been discussed at a multidisciplinary meeting?
- What services are available to help me and my family cope?
- Am I entitled to any benefits?
- Can daily routines continue? Driving a car? Exercising? Working?
- Should I think about a second opinion?
- Are there any clinical trials suitable for me?
- How do I explain this to my family? My young children? Elderly parents?
- Do I have to agree/decide now?
- If this was your family member, would you recommend this plan?
- What happens next?

## Sources



### brainstrust

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### 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](http://nice.org.uk/guidance/ng99)

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

[nice.org.uk/guidance/CSG10](http://nice.org.uk/guidance/CSG10)

### European Society for Medical Oncology (ESMO)

#### ESMO Clinical Practice Guidelines: High-Grade Malignant Glioma

[esmo.org/Guidelines/Neuro-Oncology/High-Grade-Malignant-Glioma](http://esmo.org/Guidelines/Neuro-Oncology/High-Grade-Malignant-Glioma)

### Cancer Council Australia/Australian Cancer Network/Clinical Oncological Society of Australia

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### Cancer Society of New Zealand

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## References



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### 2. Guidance for implementing high-quality multidisciplinary meetings

[health.govt.nz/system/files/documents/publications/guidance-implementing-high-quality-multidisciplinary-meetings-oct12-v3.pdf](http://health.govt.nz/system/files/documents/publications/guidance-implementing-high-quality-multidisciplinary-meetings-oct12-v3.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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### Get in touch for more information



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