

# High-grade glioma

Your guide to best cancer care



## About this guide

Being told you have high-grade glioma (a type of brain cancer) or might have high-grade glioma can be overwhelming. A lot can happen quickly, and you might have lots of questions. This resource can help to guide you and your family and friends through this experience.

## Information and support

**Cancer Council:** For information and support, call Cancer Council on **13 11 20** to talk to an experienced healthcare professional or visit [www.cancer.org.au](http://www.cancer.org.au).

For more information about high-grade glioma, look for Cancer Council's Understanding Brain Tumours booklet on your local Cancer Council website.

For more information and patient support visit: **Brain Tumour Alliance Australia** [www.curebraincancer.org.au/home](http://www.curebraincancer.org.au/home).

**Cure Brain Cancer Foundation** [www.curebraincancer.org.au](http://www.curebraincancer.org.au).

**Translating and Interpreting Service (TIS):** If you need a translator, call TIS on **13 14 50** or visit [www.tisnational.gov.au](http://www.tisnational.gov.au).

## Initial tests and referral

### Symptoms

Your general practitioner (GP) should do a check-up to see if they can find what is making you feel unwell. They will ask you about any symptoms you might be having. For example, you might have headaches in the morning or that last all day.

**If you have any sudden symptoms like a seizure you should go to a hospital straight away.**

### Initial tests you may have

**Physical examination.** Your doctor will do a check-up and tests to check your nervous system.

**Computed tomography (CT) scan.** Computers and x-rays are used to make a detailed picture of the brain.

**Magnetic resonance imaging (MRI).** A scan where a powerful magnet and radio waves are used to make a detailed picture of the brain.

### Referrals

If your GP has concerns, you will be referred to a specialist (neurosurgeon) at a public hospital or in private practice for more tests. Neurosurgeons are doctors who are highly trained in high-grade glioma.



**You can bring a family member or friend with you to your appointments.**



### Timeframes

You should be referred to a specialist **within 24 hours** of your GP appointment.

If you can't get an appointment within this time, follow up with your GP.



### Questions you might want to ask

- Should I go straight to an emergency department?
- Can I choose whether I go to a public hospital or private practice?
- Can I choose the specialist I see?
- How much will appointments cost me?

## Diagnosis and grading

The specialist will do more tests to see if you have high-grade glioma. This process of working out if you have a medical problem is called making a **diagnosis**.

You might have one test or a mix of tests:

**MRI.** If you haven't already had one.

**CT scan.** If you haven't already had one.

**Positron emission tomography (PET) scan.** A small amount of radioactive material is injected and your whole body is scanned to show where the cancer is.

**Surgical biopsy.** A biopsy is where a small sample of the glioma is cut out so it can be tested. A small opening is made in the skull. The specialist will use a needle to take a sample of the glioma. The specialist might need to remove a bigger piece of the skull to get to the glioma. This is done under anaesthetic so you cannot feel it. The sample is sent to a laboratory so they can see if it is cancer.

These tests will give the specialist more information about the glioma such as how the cancer is growing or if it has spread. This is called **grading**. **Grading** helps to work out the best treatment for you.



### Timeframes

Results should be available **within three days** of having a test.



### Questions you might want to ask

- What is high-grade glioma?
- What tests will I have?
- How much will tests/appointments cost?
- Where should I be treated? Do I have a choice?
- What grade is my cancer?
- What support services are available to me?

## Treatment

There are several ways to treat high-grade glioma. Your specialist will talk to you about your treatment options.

You will be treated by a team of experts, and you may need more than one treatment type to get the best results. The team will work with you and your family or carer to plan your treatment.

You might have one treatment or a mix of treatments:

**Surgery** is where the cancer is cut out. It is the most common treatment for people with high-grade glioma.

**Radiation therapy** uses x-rays to kill cancer cells and stop the cancer growing. Radiation therapy might be used alone, or with chemotherapy or drug therapy.

**Chemotherapy or drug therapy** uses drugs to kill cancer cells and stop the cancer growing. It might be used after surgery, with radiation therapy or after radiation therapy.

**Steroids and anticonvulsants** are medicines to stop you from having seizures. They might be used to reduce your symptoms.

For more information visit [www.cancer.org.au/cancer-information/treatment](http://www.cancer.org.au/cancer-information/treatment).

Supportive care (treatment or services that support you through a cancer experience) are also available.



### Timeframes

Treatment should start **immediately** for most cases or **within four weeks (if not urgent)** of agreeing to your treatment plan.



**You can ask your GP for a referral to another specialist for a second opinion.**

## Clinical trials

You may be offered to take part in a clinical trial. Clinical trials are used to test whether new treatments are safe and work better than current treatments. Many people with cancer are now living longer, with a better quality of life, because of clinical trials.

For more information visit [www.australiancancertrials.gov.au](http://www.australiancancertrials.gov.au).

## Complementary therapies

Speak to your healthcare team about any complementary therapies (including dietary supplements like vitamins) you use or would like to use. Something as common as vitamins might not work well with your treatment.



### Questions you might want to ask

- What treatment do you recommend?
- Where will I have to go to have treatment?
- What will treatment cost and how much of the cost will I have to pay myself?
- What activities/exercise will help me during and after treatment?
- Can I still work?
- How will the treatment affect my day-to-day life?
- Who are the people in my team and who is my main contact person?
- What side effects could I have from treatment?
- Who do I contact if I am feeling unwell or have any questions?
- Will treatment affect my ability to have a child?



## Decisions about cost

You may have to pay for some appointments, tests, medications, accommodation, travel or parking.

Speak with your GP, specialist or private health insurer (if you have one) to understand what is covered and what your out-of-pocket costs may be.

If you have concerns about costs talk to your healthcare team or a social worker about:

- being bulk-billed or being treated in the public system
- help with accommodation during treatment
- the possible financial impact of your treatment.

You can call Cancer Council on **13 11 20** to speak to a healthcare professional about financial support.

For more information about costs, visit [www.cancer.org.au/support-and-services/practical-and-financial-assistance](http://www.cancer.org.au/support-and-services/practical-and-financial-assistance) and [www.cancer.org.au/support-and-services/practical-and-financial-assistance/what-will-i-have-to-pay-for-treatment](http://www.cancer.org.au/support-and-services/practical-and-financial-assistance/what-will-i-have-to-pay-for-treatment).

## Recovery

Cancer treatment can lead to a range of physical and emotional changes.

### Follow-up care plan

Your healthcare team will work with you to make a plan for you and your GP. This plan will explain:

- who your main contact person is after treatment
- how often you should have check-ups and what tests this will include
- identifying and dealing with side-effects of treatment
- how to get help quickly if you think the cancer has returned or got worse.

Many people express feeling anxious that the cancer will return. Your specialist and healthcare team will talk with you about your needs and refer you to healthcare professionals and/or community support services.

Other information you may get:

- signs and symptoms to look out for if the cancer returns
- late effects of treatment and the specialists you may need to see
- how to make healthy lifestyle choices to give you the best chance of recovery and staying well.

For more information visit [www.cancer.org.au/cancer-information/after-a-diagnosis/after-cancer-treatment](http://www.cancer.org.au/cancer-information/after-a-diagnosis/after-cancer-treatment).



#### Questions you might want to ask

- Who should I contact if I am feeling unwell?
- What can I do to be as healthy as possible?
- Where can I get more help?

## Living with advanced cancer

### If cancer returns

It is very common for high-grade glioma to come back after treatment. Cancer can also appear somewhere different in your body.

If cancer returns, you may be referred to the specialist or the hospital where you were first treated, or to a different specialist.

Treatment will depend on how far the cancer has spread, how fast-growing it might be and the symptoms you are experiencing.



#### Questions you might want to ask

- Where is the cancer and has it spread?
- What are my treatment options?
- What are the chances that the treatment will work this time?
- Is there a clinical trial available?
- Where else can I get support?

### Advance care planning

Your GP or healthcare team may talk with you, your family and carer about your future treatment and medical needs.

### Advance care directive

Sometimes known as a living will, an advance care directive is a legally binding document that you prepare to let your family and healthcare team know about the treatment and care you might want or not want in case you become too unwell to make those decisions yourself. For more information visit [www.advancecareplanning.org.au](http://www.advancecareplanning.org.au).

### Palliative care

Your specialist may refer you to palliative care services, but this doesn't always mean end-of-life care. Today people can be referred to these services much earlier if they're living with cancer or if their cancer returns. Palliative care can help you to live as well as you can including managing pain and symptoms. This care may be at home, in a hospital or at another location you choose.

Speak to your GP or specialist or visit [www.palliativecare.org.au](http://www.palliativecare.org.au).

### Making treatment decisions

You may decide not to have treatment at all, or to only have some treatment to reduce pain and discomfort. You may want to discuss your decision with your healthcare team, GP, family and carer. For more information visit [www.cancer.org.au/cancer-information/treatment/advanced-cancer-treatment](http://www.cancer.org.au/cancer-information/treatment/advanced-cancer-treatment).



#### Questions you might want to ask

- What can you do to reduce my symptoms?
- What extra support can I get if my family and friends care for me at home?
- Can you help me to talk to my family about what is happening?
- What support is available for my family or carer?
- Can I be referred to a community support service?

Disclaimer: Always consult your doctor about matters that affect your health. This guide is intended as a general introduction and is not a substitute for professional medical, legal or financial advice. Information about cancer is constantly being updated and revised by the medical and research communities. While all care is taken to ensure accuracy at the time of publication, Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided above.

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This resource is based on information from the optimal care pathway for people with high-grade glioma (2nd edition), available at [www.cancer.org.au/OCP](http://www.cancer.org.au/OCP).