



What to expect during each stage of treatment and beyond

## High grade glioma

This information sheet tells you what you can ask for before, during and after your high grade glioma cancer treatment. You can ask your team for more information and support.

Working with your team means you can make sure you are getting the treatment, information and support that are right for you.

### 1. Your doctor visit

Your doctor 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 won't go away.

If your doctor thinks you might have a high grade glioma, they will send you to see a specialist within the next day for more tests. Your specialist is a doctor called a neurologist or neurosurgeon. They are trained in working with people with high grade gliomas.

Your doctor should give the specialist information on your health in the past, if someone else in your family has had cancer and your test results.

If you have any sudden symptoms like a seizure or fit you should go to the hospital straight away. At the hospital you will see a neurologist or a neurosurgeon.

Your doctor or specialist should work with you to make sure you have the information and help you need. You can ask your doctor about:

- What is happening in your body and why it could be happening
- What will or might happen

- How you are feeling and how to stay emotionally healthy
- Who you can talk to about getting the support you need
- Where you can get more information and support

You might have one test or a mix of tests:

#### Computed tomography scan (CT scan)

Computers and x-rays are used to make a detailed picture of the brain.

#### Magnetic resonance imaging scan (MRI)

A scan where magnetic fields and radio waves are used to make a detailed picture of the body.

#### Physical examination

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

**You can bring a family member or friend to your visits. You can ask your doctor for more information and support to make sure you have what you need.**

### 2. Tests

Your doctor might send you to a specialist if you haven't already seen one.

The specialist should do more tests to see if you have a high grade glioma.

This is called a diagnosis.

If you do have glioma, the tests will show how the cancer is growing or if it has spread.

## 2. Tests cont'd

You can ask the specialist:

- What tests you are going to have
- What will happen in the tests
- What the tests will tell you

You might have one test or a mix of tests:

### Computed tomography scan (CT scan)

You will have a computed tomography scan if you haven't already.

### Magnetic resonance imaging scan (MRI)

You will have a magnetic resonance imaging scan if you haven't already.

### Position emission tomography scan (PET)

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 will be cut out so that 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 the laboratory so that they can see if it is cancer.

This should be done by a surgeon who is very experienced at brain surgery.

**You can ask your doctor about finding a cancer peer support group. It can help knowing that there are other people who understand what you are going through. Your friends and family can talk to a support group for carers.**

## 3. Treatment

Your specialist should work with a team. Your team is made up of people that understand high grade glioma.

Your team will review your test results. They should ask you what you want and need. You should work together to make the best plan for your treatment.

You can ask your team:

- What treatment you are having
- Why you are having that treatment
- What will happen in that treatment
- What the treatment will do
- When your treatment will start and how long the treatment will take
- Risks and benefits of the treatment
- How you might feel during the treatment, side effects and what you can do to feel as well as possible
- What you can expect after the treatment

Your team might suggest you take part in a clinical trial. A clinical trial is used to test a new treatment, or to see if a treatment works better than another.

Complementary therapies include things like massage, acupuncture and meditation as well as other medicines you might take at the same time as your treatment. Some therapies might not work well with your treatment. Therefore, it is very important to talk to your team about any complementary therapies you are using, or would like to use.

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. This should be done by a surgeon who is very experienced at brain surgery.

**Chemotherapy** or drug therapy is where drugs are used to stop the cancer growing.

It might be used after surgery, with radiation therapy or after radiation therapy.

### 3. Treatment

**Radiation therapy** or radiotherapy is where radiation is used to stop the cancer growing.

Radiation therapy might be used alone, or with chemotherapy.

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

High grade glioma is usually incurable. This means that your treatment is unlikely to make the cancer go away completely. Most people with glioma will work with their palliative care team to manage their symptoms. Palliative care helps reduce your symptoms and any side effects of treatment and

can help you feel well. Your team is trained in working with people with glioma. You can ask for all the information and support you need.

For more information about treatment and side effects you can ask your doctor or **visit** [www.cancer.org.au/about-cancer/treatment](http://www.cancer.org.au/about-cancer/treatment)

**Your team should talk to you about your needs before, during and after your treatment. You can ask for information and support at any time to make sure you have everything you need.**

**Your team can connect you with other services and health professionals to make sure you stay physically and emotionally healthy.**

### 4. After your treatment

After your treatment is finished, your team should give you a treatment summary. Your treatment summary has all of the information on the treatment you received:

- Tests you had to diagnose your glioma, and the results of these tests
- Treatment you had, and when you had it
- Support services and other treatment plans you received

Your team should work with you to make a plan now that your treatment is finished. You will be able to go home. You will have follow-up visits with your specialist. You and your doctor should be given a follow-up plan that includes:

- The type of ongoing care that is best for you
- Plans for managing any side effects of treatment
- How to get help quickly if you need it

### 5. Living with cancer

#### Side effects

Some people get side effects during and after their treatment. Side effects are your body responding to the treatment you are having. They are normal, but can make you feel unwell.

You might have side effects straight away, not at all, or months after your treatment.

You can talk to your doctor about your side effects and get information and support to help you feel well or **visit** [www.cancervic.org.au/about-cancer/survivors/long-term-side-effects](http://www.cancervic.org.au/about-cancer/survivors/long-term-side-effects)

#### Advance care plan

Your team might work with you to make an advance care plan. An advance care plan is a way of setting out your wishes and making

sure everyone knows what you want in future medical care.

You can talk to your doctor about making an advance care plan together or **visit** [www.advancecareplanning.org.au](http://www.advancecareplanning.org.au)

#### Palliative care

Palliative care is the treatment used at different stages of your treatment to help you feel well. Palliative care can help with pain relief, to reduce your symptoms and to improve your quality of life.

You can talk to your doctor about the type of palliative care that is best for you or **visit** [www.palliativecare.org.au](http://www.palliativecare.org.au)

## 5. Living with cancer cont'd

### Cost

There are costs at every stage of your cancer including treatment, accommodation and travel. You might have costs if you are having treatment in a private health service even if you have private health insurance. You can talk to your team and your private health insurer if you have questions about the cost of each treatment you might have. You can also talk to the social worker at your hospital.

You can talk to your doctor about the cost of your treatment or **visit** [www.canceraustralia.gov.au/](http://www.canceraustralia.gov.au/)


[affected-cancer/living-cancer/dealing-practical-aspects-cancer/costs-treatment](#)

You can talk to your doctor about the cost of accommodation and travel or **visit** [www.cancercouncil.com.au/get-support/practical-support-services](http://www.cancercouncil.com.au/get-support/practical-support-services)

**There are a lot of things to think about when you have high grade glioma. There is also a lot of information and support. It is important that you do what is right for you. You can work with your team to make sure you have the best care.**

## Information and support

### Cancer Council

- You can talk to a cancer nurse: **13 11 20**
-  If you need an interpreter: **13 14 50**

### Carers Australia

- Information and support for carers: **1800 242 636**

