



## What to expect during each stage of treatment and beyond

### High grade glioma support

For information about brain cancer or where to go for support call the Cancer Council on **13 11 20**.

Qualified cancer nurses can answer your questions about the effects of cancer, explain what will happen during treatment or link

you to support groups and other community resources.

If you need an interpreter, call TIS (the Translating and Interpreting Service) on 13 14 50. For support and advice for carers, call the Carers Association on 1800 242 636.

## 1. Initial investigations and referral

Your general practitioner (GP) will assess your symptoms (for example, unexplained morning headache, persistent new headaches) and if high grade glioma is suspected, you will be referred to a specialist for further testing within 24 hours.

Some people have sudden symptoms (for example a seizure), and go directly to the hospital's emergency department. In this instance you will require urgent evaluation by a neurologist or neurosurgeon to assess the cause.

Your doctor (GP and/or specialist) should also discuss your needs (including physical, psychological, social and information needs) and recommend sources of reliable information and support.

If high grade glioma is suspected, you will be referred to a neurosurgeon for further testing, if this has not already been done.

#### Tests you may have:

##### Computed tomography (CT) scan

Computer technology and x-rays are used to create detailed images of the brain.

##### Magnetic resonance imaging (MRI) scan

Magnetic fields and radio waves are used to take pictures of inside the body.

##### Physical examination

Your doctor will conduct a number of physical tests to check your nervous system.

**It can be helpful to bring a family member or friend with you to your appointments.**

## 2. Diagnosis and staging

The specialist will discuss your test results with you and options for further testing. You should have a CT scan if you haven't already. This is to find out whether cancer is present and, if it is, its stage of development and if it has spread.

#### Further tests you may have:

Some people have further tests such as an MRI scan, a PET scan or a biopsy.

##### Surgical biopsy

In some cases, the neurosurgeon makes a small opening in the skull and inserts a needle to take a sample. In other cases, the neurosurgeon removes a larger part of the skull to get to the tumour. It is important that this procedure is performed by a neurosurgeon with experience in the treatment of brain tumours.

**It can also be helpful to contact cancer peer support groups and support groups for carers.**

## 3. Treatment

To ensure you receive the best care, your specialist will arrange for a team of health professionals to review your test results and plan your treatment based on your preferences and needs.

The team will be made up of health professionals who have experience managing and supporting a person with high grade glioma. Your specialist will tell you when the team will be discussing your case.

Your team should discuss the different treatment options with you including the likely outcomes, expected timeframes, possible side effects, and the risks and benefits. Your doctor may also suggest you consider taking part in a clinical trial. You might want to ask for more time before deciding on your treatment.

Let your team know about any complementary therapies you are using or thinking about trying.

Some therapies may not be appropriate, depending on your medical treatment.

#### Treatment options for high grade glioma:

For the majority of people, these treatments are used at different stages to relieve various symptoms and help to improve quality of life.

**Surgery** is the most common treatment for people with high grade glioma. It is important that surgery is performed by a neurosurgeon with experience in the treatment of brain tumours and performs several operations every year.

**Chemotherapy** may be given to you after surgery in combination with radiation therapy and/or following radiation therapy.

**Radiation therapy** (also called radiotherapy) may be given to you with or without chemotherapy.

### 3. Treatment cont'd

Medication, such as steroids or anticonvulsants (anti-seizure medication), may also be given to reduce symptoms.

#### Palliative treatment

High grade glioma is usually incurable but longer-term survivors do exist. As such, most people with high grade glioma have a palliative

care team who work in collaboration with their neuro-oncology team to assist with symptom management. It is valuable to have a palliative care team who has experience with this disease to ensure that your physical and emotional needs are being met.

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

### 4. After treatment

After your primary treatment is completed, your doctor should provide you with a treatment summary that details the care you received, including:

- diagnostic tests performed and their results
- types of treatment used and when they were performed
- treatment plans from other health professionals
- support services provided to you.

The majority of patients will be discharged into the community and generally need to see a specialist for regular followup appointments.

You and your GP should receive a follow-up care plan that tells you about:

- the type of ongoing care that is best for you
- care plans for managing any side effects of treatment, should they occur
- how to get specialist medical help quickly if required.

If you need extra help after treatment, your GP or specialist can discuss your needs with you and refer you to appropriate health professionals and/or community organisations.

### 5. Living with cancer

**Side effects:** Some people experience side effects that continue beyond the end of treatment. Side effects sometimes might not begin until months after treatment has finished.

For more information about side effects ask your doctor 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 doctor may discuss with you the option of developing an advance care plan. An advance care plan is a formal way of setting out your wishes for future medical care.

For more information about advance care planning ask your doctor or **visit** [www.advancecareplanning.org.au](http://www.advancecareplanning.org.au)

**Palliative care:** This type of treatment will be used at different stages to reduce your symptoms or to help improve your quality of life.

For more information about palliative care ask your doctor or **visit** [www.palliativecare.org.au](http://www.palliativecare.org.au)

### 6. Questions of cost

There can be cost implications at each stage of the cancer care pathway, including costs of treatment, accommodation and travel. There can be substantial out-of-pocket costs if you are having treatment in a private health service, even if you have private health insurance. You can discuss these costs with your doctor and/or private health insurer for each type of treatment you may have. If you are experiencing financial difficulties due to your cancer treatment you can contact the social worker at your local hospital.

For more information about cost of treatment **visit** [www.canceraustralia.gov.au/affected-cancer/living-cancer/dealing-practical-aspects-cancer/costs-treatment](http://www.canceraustralia.gov.au/affected-cancer/living-cancer/dealing-practical-aspects-cancer/costs-treatment)

For more information about accommodation and travel costs **visit** [www.cancercouncil.com.au/get-support/practical-support-services](http://www.cancercouncil.com.au/get-support/practical-support-services)

