

# Optimal care pathway for people with high-grade glioma

## Quick reference guide



Support: Assess supportive care needs at every step of the pathway and refer to appropriate health professionals or organisations.

The optimal care pathways describe the standard of care that should be available to all cancer patients treated in Australia. The pathways support patients and carers, health systems, health professionals and services, and encourage consistent optimal treatment and supportive care at each stage of a patient's journey. Seven key principles underpin the guidance provided in the pathways: patient-centred care; safe and quality care; multidisciplinary care; supportive care; care coordination; communication; and research and clinical trials.

This quick reference guide provides a summary of the *Optimal care pathway for people with high-grade glioma*.

Please note that not all patients will follow every step of the pathway.

### Step 1: Prevention and early detection

#### Prevention

The causes of high-grade glioma are not fully understood, and there is currently no clear prevention strategy. The only known cause is ionising radiation, but these cases are rare.

#### Risk factors

- Age (over 40 years)
- Male gender
- Race – twice as common in people of Caucasian descent
- Exposure to ionising radiation, vinyl chloride, pesticides, petroleum refining, synthetic rubber manufacturing

#### Rare familial genetic syndromes such as:

- neurofibromatosis type 1 and 2
- Li-Fraumeni cancer syndrome
- Turcot syndrome
- multiple endocrine neoplasia type 1
- Lynch syndrome
- Gorlin syndrome
- tuberous sclerosis complex
- Cowden's disease.

#### Screening recommendations

Screening has not been proven to be beneficial in detecting high-grade glioma.

#### Checklist

- Recent weight changes discussed and weight recorded
- Alcohol intake discussed and recorded and support for reducing alcohol consumption offered if appropriate
- Smoking status discussed and recorded and brief smoking cessation advice offered to smokers
- Physical activity recorded
- Referral to a dietitian, physiotherapist or exercise physiologist considered
- Education on being sun smart considered

### Step 2: Presentation, initial investigations and referral

#### Signs and symptoms

While symptoms are often non-specific, investigate the following signs and symptoms:

- increasing headaches, persistent new headaches, vomiting, unexplained morning headaches
- seizures
- blackouts or other alterations in conscious state
- poor coordination
- visual deterioration or other focal neurological symptoms
- progressive weakness
- change in behaviour
- change in memory
- confusion, drowsiness

- speech disturbance
- other unexplained neurological symptoms including major personality/behavioural changes.

#### General practitioner

All patients who present with focal neurological symptoms, a first seizure or recurring headaches will require urgent neuroimaging and evaluation by a neurologist or neurosurgeon to establish the cause. If an initial CT scan of the brain is negative, but there is still a clinical concern, specialist referral and/or MRI should be performed urgently - posterior fossa and temporal lobe lesions or more infiltrative lesions may be missed on a CT scan. Repeat MRI imaging with gadolinium contrast in 4–8 weeks if symptoms do not resolve.

#### Checklist

- MRI if symptoms suggest cancer
- Signs and symptoms recorded
- Supportive care needs assessment completed and recorded, and referrals to allied health services actioned as required
- Patient notified of support services such as Cancer Council 13 11 20
- Referral options discussed with the patient and/or carer including cost implications

## Step 2: Presentation, initial investigations and referral continued

Many patients will present directly to an emergency department with a catastrophic new neurological problem or seizure and will require urgent neurosurgical evaluation.

### Referral options

At the referral stage, the patient's GP or other referring doctor should advise the patient about their options for referral, waiting periods, expertise, if there are likely to be out-of-pocket costs and the range of services available. This will enable patients to make an informed choice of specialist and health service.

### Communication

**The GP's responsibilities include:**

- explaining to the patient and/or carer who they are being referred to and why
- recommending the patient doesn't drive until they have had a neurosurgical review
- supporting the patient and/or carer while waiting for specialist appointments
- informing the patient and/or carer that they can contact Cancer Council on 13 11 20.

### Timeframe

If there is a high clinical suspicion of high-grade glioma, refer patients to an appropriate neurosurgeon affiliated with an MDT **within 24 hours** of the patient presenting with symptoms. Healthcare providers should offer clear routes of rapid access to specialist evaluation.

## Step 3: Diagnosis, staging and treatment planning

### Diagnosis and grading

All patients should undergo:

- T1- and T2-weighted fluid-attenuated inversion recovery (FLAIR), T2-weighted and post-contrast T1-weighted MRI, and diffusion-weighted imaging (DWI)
- tissue biopsy to reliably diagnose brain cancer:
  - The histological diagnosis of brain tumours should be undertaken by a neuropathologist or by an appropriately trained anatomical pathologist with experience in tumour neuropathology.
  - Tumours should be classified according to the latest World Health Organization classification of tumours of the central nervous system.

Molecular markers must be identified for an accurate diagnosis.

Grading for high-grade gliomas involves both:

- neuroimaging with MRI +/- CT
- histological testing.

### Genetic testing

The features that suggest a genetic predisposition may include:

- early age at onset
- multiple primary cancers
- a family history of similar or related cancers, neurofibromatosis type 1 or tuberous sclerosis.

If present, these features may indicate that familial genetic testing is appropriate.

### Treatment planning

All newly diagnosed patients should be discussed in a multidisciplinary meeting (MDM) **within 2 weeks** of diagnosis. However, immediate treatment is often required before a full MDM ratifies details of the management plan (which should include full details of the response assessment).

### Research and clinical trials

Consider enrolment where available and appropriate. Search for a trial <[www.australiancancertrials.gov.au](http://www.australiancancertrials.gov.au)>.

### Communication

**The lead clinician's<sup>1</sup> responsibilities include:**

- discussing a timeframe for diagnosis and treatment options with the patient and/or carer
- explaining the role of the multidisciplinary team in treatment planning and ongoing care
- providing contact details of a key contact for the patient
- encouraging discussion about the diagnosis, prognosis, advance care planning and palliative care while clarifying the patient's wishes, needs, beliefs and expectations, and their ability to comprehend the communication
- providing appropriate information and referral to support services as required
- communicating with the patient's GP about the diagnosis, treatment plan and recommendations from MDMs.

### Checklist

- Diagnosis confirmed
- Grading/molecular profiling conducted
- Full histology obtained
- Performance status and comorbidities measured and recorded
- Patient discussed at an MDM and decisions provided to the patient and/or carer
- Clinical trial enrolment considered
- Supportive care needs assessment completed and recorded, and referrals to allied health services actioned as required
- Patient referred to support services (such as Cancer Council) as required
- Treatment costs discussed with the patient and/or carer

### Timeframe

Complete diagnostic investigations **within 1 week** of referral to specialist. Note that molecular testing may take 1–2 weeks.

<sup>1</sup> Lead clinician – the clinician who is responsible for managing patient care. The lead clinician may change over time depending on the stage of the care pathway and where care is being provided.

## Step 4: Treatment

### Establish intent of treatment

- Longer term survival without expectation of cure
- Maintenance of quality of life
- Symptom palliation.

### Treatment options

- Surgery is commonly the first therapeutic approach for tumour debulking and obtaining tissue for diagnosis. All patients with presumed high-grade glioma should be considered for surgery and, at the discretion of the treating neurosurgeon, maximal safe resection is encouraged.
- Residual enhancing disease should be determined within 48 hours after surgery using pre- and post-contrast MRI.
- Consider advanced surgical options to achieve maximal safe resection, such as fluorescence-assisted resection, intraoperative imaging and awake surgery.
- Consider all patients for radiation therapy and chemotherapy after surgery.
- These patients have specialised medication needs (corticosteroids, anticonvulsants, anticoagulants) and should be managed in conjunction with a specialist practitioner.

### Palliative care

Consider referral to specialist palliative care for all patients. Early referral to palliative care can improve quality of life. Referral should be based on need, not prognosis. For more, visit the Palliative Care Australia website <[www.palliativecare.org.au](http://www.palliativecare.org.au)>.

### Communication

#### The lead clinician and team's responsibilities include:

- discussing treatment options with the patient and/or carer including the intent of treatment as well as risks and benefits
- discussing advance care planning with the patient and/or carer where appropriate
- communicating the treatment plan to the patient's GP
- providing the patient and/or carer with information about safe mobility, seizures, possible side effects of treatment, self-management strategies and emergency contacts.

### Checklist

- Intent of treatment established
- Risks and benefits of treatments discussed with the patient and/or carer
- Treatment plan discussed with the patient and/or carer
- Treatment plan provided to the patient's GP
- Treating specialist has adequate qualifications, experience and expertise
- Supportive care needs assessment completed and recorded, and referrals to allied health services actioned as required
- Early referral to palliative care considered
- Advance care planning discussed with the patient and/or carer

### Timeframe

Surgery should occur **immediately** for most cases, or **within 4 weeks** of diagnosis if not urgent (according to clinical need).

Begin radiation therapy **within 6 weeks** after surgery.

Chemotherapy or drug therapy should occur **within 6 weeks** following surgery or radiotherapy.

## Step 5: Care after initial treatment and recovery

Most high-grade glioma patients have incurable disease, but longer term survivors exist.

Patients may be discharged into the community and generally need to see a specialist for regular follow-up appointments.

### Provide a treatment and follow-up summary to the patient, carer and GP outlining:

- the diagnosis, including tests performed and results
- tumour characteristics
- treatment received (types and date)
- current toxicities (severity, management and expected outcomes)
- interventions and treatment plans from other health professionals
- potential long-term and late effects of treatment and care of these
- supportive care services provided
- a follow-up schedule, including tests required and timing
- contact information for key healthcare providers who can offer support for lifestyle modification
- a process for rapid re-entry to medical services for suspected recurrence.

### Checklist

- Treatment and follow-up summary provided to the patient and/or carer and the patient's GP
- Supportive care needs assessment completed and recorded, and referrals to allied health services actioned as required

## Step 5: Care after initial treatment and recovery continued

Patients may be discharged into the community and generally need to see a specialist for regular follow-up appointments.

Follow-up by the neurosurgeon should occur 4–8 weeks after surgery. Surveillance should include regular radiological assessment with MRI.

An occupational therapy home assessment is essential to ensure palliative patients receiving home-based care are safely managed.

### Communication

**The lead clinician's responsibilities include:**

- explaining the treatment summary and follow-up care plan to the patient and/or carer
- informing the patient and/or carer about secondary prevention and healthy living
- discussing the follow-up care plan with the patient's GP.

### Checklist continued

- Patient-reported outcome measures recorded

## Step 6: Managing recurrent or progressive disease

### Detection

It is likely that a patient's current symptoms will worsen progressively, and this should be managed following discussion with the lead clinician and, as necessary, at an MDM in consultation with palliative care services.

### Treatment

Recurrence or progressive disease is common. Management will vary but may include further surgery, radiation therapy or systemic therapies. The supportive care needs of these patients are particularly important and should be reassessed.

### Advance care planning

Advance care planning is important for all patients but especially those with advanced disease.

It allows them to plan for their future health and personal care by thinking about their values and preferences. This can guide future treatment if the patient is unable to speak for themselves.

### Survivorship and palliative care

Survivorship and palliative care should be addressed and offered early. Early referral to palliative care can improve quality of life.

### Communication

**The lead clinician and team's responsibilities include:**

- explaining the treatment intent, likely outcomes and side effects to the patient and/or carer and the patient's GP.

### Checklist

- Treatment intent, likely outcomes and side effects explained to the patient and/or carer and the patient's GP
- Supportive care needs assessment completed and recorded, and referrals to allied health services actioned as required
- Advance care planning discussed with the patient and/or carer
- Patient referred to palliative care if appropriate
- Routine follow-up visits scheduled

## Step 7: End-of-life care

### Palliative care

Consider a referral to palliative care. Ensure an advance care directive is in place.

### Communication

**Lead clinician's responsibilities:**

- being open to and encouraging discussion about the expected disease course with the patient and/or carer
- establishing transition plans to ensure the patient's needs and goals are considered in the appropriate environment.

### Checklist

- Supportive care needs assessment completed and recorded, and referrals to allied health services actioned as required
- Patient referred to palliative care
- Advance care directive in place

Visit our guides to best cancer care webpage <[www.cancercareguides.org.au](http://www.cancercareguides.org.au)> for consumer guides. Visit our OCP webpage <[www.cancer.org.au/OCP](http://www.cancer.org.au/OCP)> for the optimal care pathway and instructions on how to import these guides into your GP software.