Optimal cancer care pathway for people with high-grade glioma

Quick reference guide

Please note that not all patients will follow every step of this pathway:

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

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.

Risk factors: Increasing age, male gender and rare familial genetic syndromes carry an increased risk for high-grade glioma: Cowden's disease, Turcot's syndrome, Lynch syndrome, Li-Fraumeni syndrome and neurofibromatosis type 1.

Step 2
Presentation, initial investigations and referral

Signs and symptoms:

While symptoms are often non-specific, the following should be investigated:

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

General/primary practitioner investigations: Some patients will present to an emergency department with a catastrophic new neurological problem or seizure and will require urgent neurological/neurosurgical evaluation.

All patients who present with focal neurological symptoms, first seizure, new onset or recurrent headache require urgent neuroimaging and evaluation by a neurologist/neurosurgeon.

Where initial computed tomography (CT) or magnetic resonance imaging (MRI) is negative, but there is continuing clinical concern, wspecialist referral and/or MRI should be performed.

Referral: Refer all patients with suspected high-grade glioma to a neurologist or neurosurgeon affiliated with a multidisciplinary team, optimally within 24 hours. Healthcare providers should provide clear routes of rapid access to specialist evaluation.

Communication – lead clinician to:

- inform the patient that they should not drive until they have had a neurosurgical review
- provide the patient with information that clearly describes who they are being referred to and why, and the expected timeframe for appointments
- support the patient while waiting for the specialist appointment.

Step 3
Diagnosis, staging and treatment planning

Diagnosis and staging:

- All patients should undergo a pre- and post-contrast MRI with advanced imaging techniques.
- A tissue diagnosis should be obtained in all patients.
- The histological diagnosis of brain tumours should be undertaken by a neuro-pathologist or by an appropriately trained anatomical pathologist with experience in tumour neuro-pathology.
- The identification of molecular markers (including 1p19q) is an evolving field and increasingly may impact on therapeutic decisions.

Surgical management should be within one week of referral but may be earlier or later according to clinical need.

Treatment planning: Immediate treatment is often required before a full multidisciplinary meeting 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.

Communication – lead clinician to:

- provide contact details of a key contact for the patient
- discuss a timeframe for diagnosis and treatment with the patient/carer
- explain the role of the multidisciplinary team in treatment planning and ongoing care
- provide appropriate information or refer to support services as required.

1 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.

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

Step 4

Treatment:

Establish intent of treatment:

- longer term survival
- maintenance of quality of life
- symptom palliation.

Treatment options:

- All patients should be considered for surgery by a neurosurgeon with experience in treating brain tumours. Surgery is commonly the initial therapeutic approach for tumour debulking and obtaining tissue for diagnosis.
- Ideally, the determination of residual enhancing disease should be assessed within 48 hours after surgical biopsy using pre- and post-contrast MRI.
- All patients should be considered for radiation therapy and chemotherapy.
- These patients have specialised medication needs (corticosteroids, anticonvulsants, anticoagulants) and should be managed in conjunction with a specialist practitioner.

Palliative care: Specialist palliative care is recommended for the majority of patients with high-grade gliomas. Early referral can improve quality of life. Referral should be based on need, not prognosis.

Communication – lead clinician to:

- discuss the treatment plan with the patient and carer, including the intent of treatment and expected outcomes
- discuss advance care planning with the patient/carer where appropriate
- discuss the treatment plan with the patient's general practitioner
- provide the patient and carer with information on safe mobility, seizures, possible side effects of treatment, self-management strategies and emergency contacts.

For detailed information see http://www.cancer.org.au/content/pdf/HealthProfessionals/ClinicalGuidelines/Clinical_Practice_Guidelines-Adult_Gliomas-AUG09.pdf.

Step 5

Care after initial treatment and recovery

The majority of 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 followup appointments.

The patient and their general practitioner should be provided with the following to guide care after initial treatment.

Treatment summary outlining:

- the diagnostic tests performed and results
- tumour characteristics
- the type and date of treatment(s)
- interventions and treatment plans from other health professionals
- supportive care services provided
- contact information for key care providers.

Follow-up care plan outlining:

- medical follow-up required (tests, ongoing surveillance)
- care plans for managing the late effects of treatment
- a process for rapid re-entry to medical services for suspected recurrence.

Follow-up by the neurosurgeon should occur four to eight weeks after surgery. Surveillance should include regular radiological assessment with MRI.

Communication – lead clinician to:

- explain the treatment summary and follow-up care plan to the patient/carer
- provide information about the signs and symptoms of recurrent disease.

Step 6

Managing recurrent or progressive disease

Detection: It is likely that patient's current symptoms will worsen progressively and this should be managed following discussion at a multidisciplinary clinic in consultation with palliative care specialists.

Treatment: Recurrence is very common and 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.

Communication – lead clinician to:

- explain the treatment intent, likely outcomes and side effects to the patient/carer.

Step 7

End-of-life care

Palliative care: Ensure that an advance care plan is in place. Occupational therapy home assessment is essential to ensure the safe management of palliative patients receiving home-based care.

Communication – lead clinician to:

- be open to and encourage discussion about the expected disease course with the patient/carer
- discuss palliative care options including inpatient and community-based services as well as dying at home and subsequent arrangements.

Visit www.cancerpathways.org.au for consumer friendly guides. Visit www.cancer.org.au/OCP for the full clinical version and instructions on how to import these guides into your GP software.