

Optimal cancer care pathway for people with high-grade glioma



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Foreword

The pathway for cancer patients undergoing diagnosis and treatment for cancer is complex and poorly comprehended by those involved. It usually involves multiple healthcare providers and covers a range of institutions, both public and private. The optimal cancer care pathways map this journey for specific tumour types, aiming to foster an understanding of the whole pathway and its distinct components to promote quality cancer care and patient experiences. These pathways act as a reminder that the patient is the constant in this journey and that the health system has a responsibility to deliver the care experience in an appropriate and coordinated manner.

The optimal care pathways are based on a revision of the original patient management frameworks (Department of Health 2007a), which had, for the first time, attempted to map the cancer pathway in an easily understandable form.

The purpose of this work is to improve patient outcomes by facilitating consistent cancer care based on a standardised pathway of care. The pathways are applicable to care whether it is provided in a public or private service. The principles and the expected standards of good cancer care are not expected to differ, even though treatment regimens may vary from patient to patient for a whole variety of reasons.

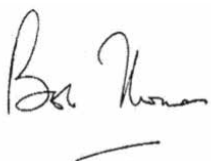
Victoria has undertaken this program of work as part of a national work plan aimed at improving cancer care. This national work plan was developed by the National Cancer Expert Reference Group (NCERG). The NCERG is a panel of experts and jurisdictional and consumer representatives that was established by the Council of Australian Governments (COAG) in 2010. In developing a national work plan for improving cancer care in Australia, the NCERG identified the value of a national approach to delivering consistent and optimal cancer care.

The NCERG has subsequently endorsed these new optimal cancer care pathways, which they agree are relevant across all jurisdictions. Each jurisdiction has been invited to adopt and co-badge these for local use.

A wide range of clinicians, peak health organisations, consumers and carers were consulted and/or participated in their development and I want to thank all concerned for their generous contributions.

I am sure that those providing cancer care will find the specific pathways useful in deciding how best to organise service delivery to achieve the best outcomes for those we care for.

Importantly, readers should note that these care pathways are not detailed clinical practice guidelines. They are not intended to constitute medical advice or replace clinical judgement.



Professor Robert Thomas OAM
Chief Advisor Cancer, Department of Health and Human Services – Victoria

Summary

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, specialist 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.

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.

Summary – optimal timeframes

Timeframes to treatment: Timeframes should be informed by evidence-based guidelines (where they exist) while recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress. The following recommended timeframes are based on expert advice from the High-Grade Glioma Working Group.

Care point	Timeframe
2.3 Referral to specialist	Urgently referred to an appropriate neurologist/neurosurgeon, optimally within 24 hours.
3.1 Diagnostic work-up	Obtain tissue diagnosis within one week of referral but may be earlier or later according to clinical need.
3.2.4 Multidisciplinary team meeting	All newly diagnosed patients should be discussed in a multidisciplinary team meeting immediately after tissue diagnosis and before beginning subsequent treatment.
4.2 Treatment options – obtaining histological diagnosis	A timely appointment to discuss the histological diagnosis should be arranged within one week of surgery.
4.2 Treatment options – commencing treatment	Referral to medical and radiation oncology as soon as feasible; usually within four weeks but extenuating circumstances may delay treatment for up to six weeks.

Intent of the optimal cancer care pathway

The optimal cancer care pathway is intended to guide the delivery of consistent, safe, high-quality and evidencebased care for people with cancer.

The pathway aligns with key service improvement priorities, including providing access to coordinated multidisciplinary care and supportive care and reducing unwanted variation in practice.

The optimal cancer care pathway can be used by health services and professionals as a tool to identify gaps in current cancer services and to inform quality improvement initiatives across all aspects of the care pathway. The pathway can also be used by clinicians as an information resource and tool to promote discussion and collaboration between health professionals and people affected by cancer.

The following key principles of care underpin the optimal cancer care pathway.

Patient-centred care

Patient- or consumer-centred care is healthcare that is respectful of, and responsive to, the preferences, needs and values of patients and consumers. Patient- or consumer-centred care is increasingly being recognised as a dimension of high-quality healthcare in its own right, and there is strong evidence that a patient-centred focus can lead to improvements in healthcare quality and outcomes by increasing safety and cost-effectiveness as well as patient, family and staff satisfaction (ACSQHC 2013).

Safe and quality care

This is provided by appropriately trained and credentialed clinicians, hospitals and clinics that have the equipment and staffing capacity to support safe and high-quality care. It incorporates collecting and evaluating treatment and outcome data to improve the patient experience of care as well as mechanisms for ongoing service evaluation and development to ensure practice remains current and informed by evidence. Services should routinely be collecting relevant minimum datasets to support benchmarking, quality care and service improvement.

Multidisciplinary care

This is an integrated team approach to healthcare in which medical and allied health professionals consider all relevant treatment options and collaboratively develop an individual treatment and care plan for each patient. There is increasing evidence that multidisciplinary care improves patient outcomes.

The benefits of adopting a multidisciplinary approach include:

- improving patient care through developing an agreed treatment plan
- providing best practice through adopting evidence-based guidelines
- improving patient satisfaction with treatment
- improving the mental wellbeing of patients
- improving access to possible clinical trials of new therapies
- increasing the timeliness of appropriate consultations and surgery and a shorter timeframe from diagnosis to treatment
- increasing the access to timely supportive and palliative care
- streamlining pathways
- reducing duplication of services (Department of Health 2007b).

Supportive care

Supportive care is an umbrella term used to refer to services, both generalist and specialist, that may be required by those affected by cancer. Supportive care addresses a wide range of needs across the continuum of care and is increasingly seen as a core component of evidence-based clinical care. Palliative care can be part of supportive care processes. Supportive care in cancer refers to the following five domains:

- physical needs
- psychological needs
- social needs
- information needs
- spiritual needs.

All members of the multidisciplinary team have a role in providing supportive care. In addition, support from family, friends, support groups, volunteers and other community-based organisations make an important contribution to supportive care.

An important step in providing supportive care is to identify, by routine and systematic screening (using a validated screening tool) of the patient and family, views on issues they require help with for optimal health and quality-of-life outcomes. This should occur at key points along the care pathway, particularly at times of increased vulnerability including:

- initial presentation or diagnosis (the first three months)
- the beginning of treatment or a new phase of treatment
- change in treatment
- change in prognosis
- end of treatment
- survivorship
- recurrence
- change in or development of new symptoms
- palliative care
- end-of-life care.

Following each assessment, potential interventions need to be discussed with the patient and carer and a mutually agreed approach to multidisciplinary care and supportive care formulated (NICE 2004).

Common indicators in patients with high-grade glioma that may require referral for support include:

- pain/headaches
- cognition impairment
- seizures
- fatigue
- alteration in vision and perceptual impairment
- behavioural change
- mobility issues such as limb weakness
- new neurological deficits
- difficulty sleeping
- distress, depression or fear
- poor performance status
- living alone or being socially isolated
- having caring responsibilities for others
- cumulative stressful life events
- existing mental health issues
- Aboriginal or Torres Strait Islander status
- being from a culturally and linguistically diverse background.

Depending on the needs of the patient, referral to an appropriate health professional(s) and/or organisation(s) should be considered including:

- a psychologist or psychiatrist
- community-based support services (such as Cancer Council Australia)
- a dietitian
- an exercise physiologist
- an occupational therapist
- a physiotherapist
- peer support groups (contact the Cancer Council on 13 11 20 for more information)
- a social worker
- nurse practitioner and/or specialist nurse
- specialist palliative care
- a genetic counsellor
- a speech therapist.

See the **appendix** for more information on supportive care and the specific needs of people with high-grade glioma.

Care coordination

Care coordination is a comprehensive approach to achieving continuity of care for patients. This approach seeks to ensure that care is delivered in a logical, connected and timely manner so the medical and personal needs of the patient are met.

In the context of cancer, care coordination encompasses multiple aspects of care delivery including multidisciplinary team meetings, supportive care screening/assessment, referral practices, data collection, development of common protocols, information provision and individual clinical treatment.

Improving care coordination is the responsibility of all health professionals involved in the care of patients and should therefore be considered in their practice. Enhancing continuity of care across the health sector requires a whole-of-system response – that is, that initiatives to address continuity of care occur at the health system, service, team and individual levels (Department of Health 2007c).

Communication

It is the responsibility of the healthcare system and all people within its employ to ensure the communication needs of patients, their families and carers are met. Every person with cancer will have different communication needs, including cultural and language differences. Communication with patients should be:

- timely
- individualised
- truthful and transparent
- consistent
- in plain language (avoiding complex medical terms and jargon)
- culturally sensitive
- active, interactive and proactive
- ongoing
- delivered in an appropriate setting and context
- inclusive of patients and their families (with the patient's consent).

In communicating with patients, healthcare providers should:

- listen to patients and act on the information provided by them
- encourage expression of individual concerns, needs and emotional states
- tailor information to meet the needs of the patient, their carer and family
- use professionally trained interpreters when communicating with people from culturally and linguistically diverse backgrounds
- ensure the patient and/or their carer and family have the opportunity to ask questions
- ensure the patient is not the conduit of information between areas of care (it is the provider's and healthcare system's responsibility to transfer information between areas of care)
- take responsibility for communication with the patient
- respond to questions in a way the patient understands
- enable all communication to be two-way.

Healthcare providers should also consider offering the patient a Question Prompt List (QPL) in advance of their consultation, and recordings or written summaries of their consultations. QPL interventions are effective in improving the communication, psychological and cognitive outcomes of cancer patients (Brandes et al. 2014). Providing recordings or summaries of key consultations may improve the patient's recall of information and patient satisfaction (Pitkethly et al. 2008).

Research and clinical trials

Where practical, patients should be offered the opportunity to participate in research and/or clinical trials at any stage of the care pathway. Research and clinical trials play an important role in establishing efficacy and safety for a range of treatment interventions, as well as establishing the role of psychological, supportive and palliative care interventions (Sjoquist & Zalberg 2013).

While individual patients may or may not receive a personal benefit from the intervention, there is evidence that outcomes for participants in research and clinical trials are generally improved, perhaps due to the rigour of the process required by the trial. Leading cancer agencies often recommend participation in research and clinical trials as an important part of patient care. Even in the absence of measurable benefit to patients, participation in research and clinical trials will contribute to the care of cancer patients in the future (Peppercorn et al. 2004).

Optimal cancer care pathway

The optimal cancer care pathway outlines seven critical steps in the patient journey. While the seven steps appear in a linear model, in practice, patient care does not always occur in this way but depends on the particular situation (such as the type of cancer, when and how the cancer is diagnosed, prognosis, management, patient decisions and the patient's physiological response to treatment).

The pathway describes the optimal cancer care that should be provided at each step. The pathway includes all high-grade glioma (grades 3 and 4).

Special considerations

High-grade glioma is usually associated with a poor prognosis and a high recurrence rate as they are fast-growing, invasive tumours and are likely to recur. The majority of high-grade glioma patients have incurable disease, but longer term survivors exist. In the majority of cases, symptoms will worsen progressively and should be managed following discussion at a multidisciplinary clinic in consultation with palliative care specialists (Philip et al. 2013b).

Step 1: Prevention and early detection

This step outlines recommendations for the prevention and early detection of high-grade glioma.

1.1 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 (Australian Cancer Network 2009).

1.2 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 (Stupp et al. 2014).

1.3 Early detection

1.3.1 Screening

There is no population-based screening program for high-grade glioma. There is no evidence of benefit of screening.

Step 2: Presentation, initial investigations and referral

This step outlines the process for establishing a diagnosis and appropriate referral. The types of investigation undertaken by the general or primary practitioner depend on many factors, including access to diagnostic tests and medical specialists and patient preferences.

2.1 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.

2.2 Assessments by the general or primary medical practitioner

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 to establish the cause of these symptoms (Australian Cancer Network 2009).

Where initial CT or MRI is negative, but there is continuing clinical concern, specialist referral and/or MRI should be performed.

2.3 Referral

All patients with suspected high-grade glioma should be referred to a neurologist or neurosurgeon who works in an environment able to undertake ongoing care and is affiliated with a multidisciplinary team (WCMICS 2009).

Healthcare providers should provide clear routes of rapid access to specialist evaluation.

Referral for suspected high-grade glioma should incorporate appropriate documentation sent with the patient including:

- a letter that includes important psychosocial history and relevant past history, family history, current symptoms, medications and allergies
- results of current clinical investigations (imaging and pathology reports)
- results of all prior relevant investigations
- any prior imaging, particularly a hard copy or CD of previous chest x-rays and CT scans where online access is not available (lack of a hard copy should not delay referral)
- notification if an interpreter service is required.

Timeframe for referral to a specialist

Timeframes for referral to a specialist should be informed by evidence-based guidelines (where they exist) while recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress.

The following recommended timeframes are based on expert advice from the High-Grade Glioma Working Group¹:

- If considered to have a high-grade glioma, the patient should be urgently referred to an appropriate neurologist/neurosurgeon, optimally within 24 hours.

The supportive and liaison role of the GP and practice team in this process is critical.

2.4 Support and communication

2.4.1 Supportive care

An individualised clinical assessment is required to meet the identified needs of an individual, their carer and family; referral should be as required.

In addition to common issues identified in the **appendix**, specific needs that may arise at this time include:

- treatment for physical symptoms such as seizures, headaches, pain and fatigue
- help with the emotional distress of dealing with a potential cancer diagnosis, anxiety/depression, interpersonal problems, stress and adjustment difficulties
- assistance with developing strategies to compensate for any loss of cognitive function
- advice about safe driving
- guidance for financial and employment issues (such as loss of income and having to deal with travel, and accommodation requirements for rural patients and caring arrangements for other family members)
- appropriate information for people from culturally and linguistically diverse backgrounds
- allied health evaluation as appropriate.

2.4.2 Communication with the patient, family and carer

Effective communication is essential at every step of the care pathway. Effective communication with the patient and carer is particularly important given the prevalence of low health literacy in Australia (estimated at 60 per cent of Australian adults) (ACSQHC 2013).

The general or primary practitioner should:

- 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, the reason for referral and the expected timeframe for appointments
- support the patient while waiting for the specialist appointment.

¹ The multidisciplinary experts group who participated in a clinical workshop to develop content for the malignant glioma optimal care pathway are listed in the acknowledgements list.

Step 3: Diagnosis, assessment and treatment planning

Step 3 outlines the process for confirming the diagnosis and planning subsequent treatment. The guiding principle is that interaction between appropriate multidisciplinary team members should determine the treatment plan.

3.1 Diagnostic workup

- 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 (Australian Cancer Network 2009).
- The identification of molecular markers (including 1p19q) is an evolving field and increasingly may impact on therapeutic decisions.

Timeframe for obtaining a tissue diagnosis

Timeframes for diagnosis should be informed by evidence-based guidelines (where they exist) while recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress.

The following recommended timeframes are based on expert advice from the High-Grade Glioma Working Group.² Timeframes for surgical management should be within one week of referral but may be earlier or later according to clinical need.

3.2 Treatment planning

3.2.1 Responsibilities of the multidisciplinary team

The responsibilities of the multidisciplinary team are to:

- nominate a team member to coordinate patient care and identify this person to the patient
- nominate a team member to be the lead clinician (the lead clinician may change over time depending on the stage of the care pathway and where care is being provided) and identify this person to the patient (if different from the care coordinator)
- develop and document an agreed treatment plan at the multidisciplinary team meeting
- communicate/circulate the agreed multidisciplinary team treatment plan to relevant team members, including the patient's general practitioner.

² The multidisciplinary experts group who participated in a clinical workshop to develop content for the malignant glioma optimal care pathway are listed in the acknowledgements list.

3.2.2 Responsibilities of individual team members

The general or primary medical practitioner who made the referral is responsible for the patient until care is passed to another practitioner.

The general or primary medical practitioner may play a number of roles in all stages of the cancer pathway including diagnosis, referral, treatment and coordination and continuity of care as well as providing information and support to the patient and their family.

The care coordinator is responsible for ensuring there is continuity throughout the care process and coordination of all necessary care for a particular phase. The care coordinator may change over the course of the pathway.

The lead clinician is responsible for overseeing the activity of the team.

3.2.3 Members of the multidisciplinary team for high-grade glioma

The multidisciplinary team should comprise the core disciplines integral to providing good care. Team membership will vary according to cancer type but should reflect both clinical and psychosocial aspects of care. Additional expertise or specialist services may be required for some patients (Department of Health 2007b).

Team members may include a:

- care coordinator (as determined by multidisciplinary team members)*
- medical oncologist / neuro-oncologist*
- neuropathologist*
- neuroradiologist*
- neurosurgeon*
- nurse (with appropriate expertise)*
- radiation oncologist*
- social worker*
- clinical trials coordinator
- dietitian
- general practitioner
- neurologist
- neuropsychologist
- nuclear medicine physician
- occupational therapist
- palliative care specialist
- pharmacist
- physiotherapist
- psychiatrist
- rehabilitation physician
- speech therapist.

* Core members of the multidisciplinary team are expected to attend most multidisciplinary team meetings either in person or remotely.

3.2.4 The optimal timing for multidisciplinary team planning

All newly diagnosed patients should be discussed in a multidisciplinary team meeting immediately after tissue diagnosis and before beginning subsequent treatment. For certain tumour subgroups (brainstem glioma, eloquent area, multiple tumours, unusual tumours), involvement of the multidisciplinary team should occur before surgery.

The level of discussion may vary depending on both the clinical and psychosocial factors.

There may also need to be a review of existing treatment plans for patients who have been discussed previously.

Results of all relevant tests and imaging should be available for the multidisciplinary team discussion. The care coordinator or treating clinician should also present information about the patient's concerns, preferences and social circumstances at the meeting (Department of Health 2007c).

3.2.5 Referral to clinical genetics

Referral to a clinical genetics service should be considered if the patient or their first- or second-degree relatives have features or family history suggestive of neurofibromatosis type 1 or tuberous sclerosis, or if there is a personal or family history (first- or second-degree relatives) of:

- premenopausal breast cancer, sarcoma, acute leukaemia or paediatric cancer (especially where two or more of these other cancer types have occurred and where one or more cases have occurred before age 45)
- bowel, uterine, stomach, ovarian, biliary/pancreatic or small intestinal cancer or transitional cell carcinoma of the upper ureter (especially where two or more cases of these other cancers have occurred and/or where one or more of these have been diagnosed before age 50) (Australian Cancer Network 2009).

3.3 Research and clinical trials

All patients with a high-grade glioma should be offered the opportunity to participate in a clinical trial or clinical research if appropriate (Field et al. 2013).

Cross-referral between clinical trials centres should be encouraged to facilitate participation.

Culturally and linguistically diverse patients have significantly lower rates of recruitment, accrual and retention in cancer clinical trials. Enhancing research participation of culturally and linguistically diverse communities ensures not only wider understanding of genetic heterogeneity to improve glioma outcomes but also equity in access to care (Lwin et al. 2014).

- Cooperative Trials Group for Neuro-oncology (COGNO) coordinates large-scale multi-centred neuro-oncology trials. For more information visit <www.cogno.org.au>.
- Australian Cancer Trials is a national clinical trials database. It provides information on the latest clinical trials in cancer care, including trials that are recruiting new participants. For more information visit <www.australiancancertrials.gov.au>.

3.4 Support and communication

3.4.2 Supportive care

The supportive care requirements for patients with high-grade glioma is frequently punctuated by significant change – particularly at diagnosis and at times of recurrence or disease progression. Although patients may remain clinically stable for prolonged periods these fluctuating episodes of clinical deterioration may be coupled with prognostic uncertainty. As such, providers need to be responsive at times of disease plateau or between treatments when surveillance is less intensive but disability may be ongoing (Philip et al. 2013a).

Screening with a validated screening tool (such as the National Comprehensive Cancer Network Distress Thermometer and Problem Checklist), assessment and referral to appropriate health professionals or organisations is required to meet the identified needs of an individual, their carer and family. Early assessment by allied health professionals is recommended.

Other supportive care needs

In addition to the other common issues outlined in the **appendix**, specific needs that may arise at this time include the following.

Physical

- Information about seizures should be provided to the family and carers. This information should cover what to expect and what to do in the event of a seizure, such as maintaining the person's airway and removing dangerous objects from the area. This may help relieve the anxiety of family and carers.
- Headaches can be severe, and specific management by the medical specialist is generally required.
- Corticosteroids are commonly used with benefit. Because they are given in high doses over prolonged periods, significant side effects are likely. Treat with the lowest effective dose. Patients should know who to contact in case of emergency.
- Fatigue/change in functional abilities is a common symptom, and patients may benefit from referral to occupational therapy.

Psychological

- Patients may require help with psychological and emotional distress while adjusting to the diagnosis, treatment phobias, existential concerns, stress, difficulties making treatment decisions, anxiety/depression, loss of previous life roles including driving, and interpersonal problems.

Cognitive dysfunction and personality and behavioural changes

- Alteration in cognitive functioning, behaviour and personality are common with gliomas and are often unrecognised but can impact significantly on normal activities. Ongoing assessment and management from neuropsychologists, neuropsychiatrists or occupational therapy should be considered if feasible (Australian Cancer Network 2009).

Social/practical

- Support the patient to attend appointments.
- Provide guidance about financial and employment issues (such as loss of income and having to deal with travel and accommodation requirements for rural patients and caring arrangements for other family members).

Information

- Provide appropriate information to patients and carers about how to manage alterations in cognitive function and potential changes in behaviour
- Provide appropriate information for people from culturally and linguistically diverse backgrounds.
- Give advice about safe driving.

Spiritual needs

- Multidisciplinary teams should have access to suitably qualified, authorised and appointed spiritual caregivers who can act as a resource for patients, carers and staff.
- Patients with cancer and their families should have access to spiritual support appropriate to their needs throughout the cancer journey.

The neurosurgical review should include an assessment of fitness to drive as per the Australian guidelines, which are available at <<http://www.austroads.com.au/drivers-vehicles/assessing-fitness-to-drive>>.

3.4.2 Prehabilitation

Evidence indicates that prehabilitation of newly diagnosed cancer patients prior to starting treatment can be beneficial (noting this may only be feasible for a minority of patients with high-grade glioma given the urgency of commencing treatment).

Medications should be reviewed at this point to ensure optimisation and to improve adherence to medicines used for comorbid conditions.

3.4.2 Communication with the patient, family and carer

The lead clinician should:

- establish if the patient has a regular or preferred general practitioner
- provide contact details of a key contact for the patient
- discuss a timeframe for diagnosis and treatment with the patient and carer
- discuss the benefits of multidisciplinary care, and make the patient aware that their health information will be available to the team for the discussion at the multidisciplinary team meeting
- offer individualised high-grade glioma information that meets the needs of the patient and carer (this may involve advice from health professionals as well as written and visual resources)
- offer advice on how to access information and support from websites, community and national cancer services and support groups for both patients and carers
- use a professionally trained interpreter to communicate with people from culturally or linguistically diverse backgrounds
- recognise the ability of the patient and carers to comprehend the communication
- provide appropriate information to the person's carer regarding managing altered cognitive function and/or behaviour (when there are significant cognitive impairments, carers are likely to assume a central role in communication and decision making (Australian Cancer Network 2009))
- provide information regarding safe mobility to carers as well as patients.

3.4.3 Communication with the general practitioner

The lead clinician should:

- ensure regular and timely (within a week) communication with the person's general practitioner regarding the treatment plan and recommendations from multidisciplinary team meetings
- notify the general practitioner and family/carer if the person does not attend clinic appointments
- gather information from the general practitioner including their perspective on the person (psychological issues, social issues and comorbidities) and locally available support services
- contribute to the development of a chronic disease and mental healthcare plan as required
- discuss management of shared care
- invite the general practitioner to participate in multidisciplinary team meetings (consider using video or teleconferencing).

Step 4: Treatment

Step 4 outlines the treatment options for high-grade glioma. For detailed information on treatment options refer to the Australian Cancer Network's *Clinical practice guidelines for the management of adult gliomas: astrocytomas and oligodendrogliomas* at <http://www.cancer.org.au/content/pdf/HealthProfessionals/ClinicalGuidelines/Clinical_Practice_Guidelines-Adult_Gliomas-AUG09.pdf>.

4.1 Treatment intent

The intent of treatment can be defined as one of the following:

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

The morbidity and risks of treatment need to be balanced against the potential benefits.

The lead clinician should discuss treatment intent and prognosis with the patient and their family/carer prior to beginning treatment.

Advance care planning should be initiated with patients and their carers as there can be multiple benefits such as ensuring a person's preferences are known and respected after the loss of decision-making capacity (AHMAC 2011).

4.2 Treatment options

The advantages and disadvantages of each treatment and associated potential side effects should be discussed with the patient and their carer/family.

4.2.1 Surgery

All patients should be considered for surgery by a neurosurgeon with experience in treating brain tumours and involvement in multidisciplinary care. Surgery is commonly the initial therapeutic approach for tumour debulking and obtaining tissue for diagnosis.

Training, experience and treatment centre characteristics

The training and experience required of the surgeon is as follows:

- neurosurgeon (FRACS or equivalent) with adequate training and experience and institutional cross-credentialling and agreed scope of practice within this area (ACSQHC 2004).

Hospital or treatment unit characteristics for providing safe and quality care include:

- a full neurosurgical service for cranial neurosurgery with MRI, post-operative high dependency unit and intensive care unit
- appropriate nursing and theatre resources to manage complex neurosurgery
- 24-hour medical staff availability
- 24-hour operating room access.

High-volume centres generally have better clinical outcomes (Barker et al. 2005). Centres that do not have sufficient caseloads should establish processes to routinely refer surgical cases to a high-volume centre.

4.2.2 MRI post-operative assessment

Ideally, the determination of residual enhancing disease should be assessed within 48 hours after surgical biopsy using pre- and post-contrast MRI in order to distinguish post-surgical contrast enhancement from residual enhancing tumour.

4.2.3 Radiation therapy

All patients should be considered for radiation therapy by a radiation oncologist with experience in treating brain tumours and involvement in multidisciplinary care. The use of MRI image fusion for treatment planning is optimal.

Training, experience and treatment centre characteristics

Training and experience required of the appropriate specialist(s):

- radiation oncologist (Fellowship of the Royal Australian and New Zealand College of Radiologists or equivalent) with adequate training and experience with institutional credentialling and agreed scope of practice in brain cancer (ACSQHC 2004).

Radiation oncology centre characteristics for providing safe and quality care include:

- trained radiation therapists, medical physicists and radiation therapy nurses
- access to allied health, especially nutrition health and advice, occupational therapy and psychological support
- access to CT and MRI scanning for simulation and planning.

4.2.4 Chemotherapy or drug therapy

All patients should be referred to a medical oncologist or neuro-oncologist with experience in treating brain tumours and involvement in multidisciplinary care.

These patients have specialised medication needs (corticosteroids, anticonvulsants, anticoagulants) and should be managed in conjunction with a specialist practitioner.

Training, experience and treatment centre characteristics

The following training and experience is required of the appropriate specialist(s):

- Medical oncologists and neuro-oncologists (Fellowship of the Royal Australasian College of Physicians or equivalent) must have adequate training and experience with institutional credentialling and agreed scope of practice within this area (ACSQHC 2004).
- Nurses must have adequate training in chemotherapy handling, administration and disposal of cytotoxic waste.
- Chemotherapy should be prepared by a pharmacist with adequate training in chemotherapy medication, including dosing calculations according to protocols, formulations and/or preparation.
- In a setting where no medical oncologist is locally available, some components of less complex therapies may be delivered by a medical practitioner and/or nurse with training and experience with credentialling and agreed scope of practice within this area under the guidance of a medical oncologist. This should be in accordance with a detailed treatment plan or agreed protocol, and with communication as agreed with the medical oncologist or as clinically required.

Hospital or treatment unit characteristics for providing safe and quality care include:

- a clearly defined path to emergency care and advice after hours
- access to basic haematology and biochemistry testing
- cytotoxic drugs prepared in a pharmacy with appropriate facilities
- occupational health and safety guidelines regarding handling of cytotoxic drugs, including safe prescribing, preparation, dispensing, supplying, administering, storing, manufacturing, compounding and monitoring the effects of medicines (ACSQHC 2011)
- guidelines and protocols regarding safe delivery of treatment (including dealing with extravasation of drugs)
- mechanisms for coordinating combined therapy (chemotherapy and radiation therapy), especially where facilities are not collocated.

Timeframe for communicating histological diagnosis and commencing treatment

Timeframes should be informed by evidence-based guidelines (where they exist) while recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress.

The following recommended timeframes are based on expert advice from the High-Grade Glioma Working Group:³

- A timely appointment to discuss the histological diagnosis should be arranged within one week of surgery, and the patient should be clearly informed of the timeframe.
- Following diagnosis, patients should be referred in a timely manner to Radiation and Medical Oncology and treatment should begin as soon as feasible. Usually this should be within four weeks but extenuating circumstances may delay treatment for up to six weeks.

4.3 Palliative care

Given the poor prognosis of this cancer at present, for the majority of patients treatment is often given with palliative rather than curative intent. Specialist palliative care will be required for patients with high-grade glioma.

The lead clinician should ensure patients receive timely and appropriate referral to palliative care services. Referral should be based on need rather than prognosis.

- Patients may be referred to palliative care at initial diagnosis.
- Patients should be referred to palliative care at first recurrence or progression.
- Carer needs may prompt referral (Collins et al. 2013).

Early referral to palliative care can improve the quality of life for people with cancer (Haines 2011; Temel et al. 2010; Zimmermann et al. 2014). This is particularly true for poor-prognosis cancers (Cancer Council Australia 2012; Philip et al. 2013b; Temel et al. 2010). Furthermore, palliative care has been associated with the improved wellbeing of carers (Higginson & Evans 2010; Hudson et al. 2014).

Ensure carers and families receive information, support and guidance regarding their role according to their needs and wishes (Palliative Care Australia 2005).

The patient and carer should be encouraged to develop an advance care plan (AHMAC 2011).

³ The multidisciplinary experts group who participated in a clinical workshop to develop content for the malignant glioma optimal care pathway are listed in the acknowledgements list.

Further information

Refer patients and carers to Palliative Care Australia at <www.palliativecare.org.au>.

4.4 Research and clinical trials

All patients with a high-grade glioma should be offered the opportunity to participate in a clinical trial or clinical research if appropriate (Field et al. 2013).

Cross-referral between clinical trials centres should be encouraged to facilitate participation.

Culturally and linguistically diverse patients have significantly lower rates of recruitment, accrual and retention in cancer clinical trials. Enhancing research participation of culturally and linguistically diverse communities ensures not only wider understanding of genetic heterogeneity to improve glioma outcomes but also equity in access to care (Lwin et al. 2014).

- Cooperative Trials Group for Neuro-oncology (COGNO) coordinates large-scale multi-centred neuro-oncology trials. For more information visit <www.cogno.org.au>.
- Australian Cancer Trials is a national clinical trials database. It provides information on the latest clinical trials in cancer care, including trials that are recruiting new participants. For more information visit <www.australiancancertrials.gov.au>.

4.5 Complementary or alternative therapies

The lead clinician should discuss the patient's use (or intended use) of complementary or alternative therapies not prescribed by the multidisciplinary team to identify any potential toxicity or drug interactions.

The lead clinician should seek a comprehensive list of all complementary and alternative medicines being taken and explore the patient's reason for using these therapies and the evidence base.

Many alternative therapies and some complementary therapies have not been assessed for efficacy or safety. Some have been studied and found to be harmful or ineffective.

Some complementary therapies may assist in some cases and the treating team should be open to discussing the potential benefits for the individual.

If the patient expresses an interest in using complementary therapies, the lead clinician should consider referring them to health professionals within the multidisciplinary team who have knowledge of complementary and alternative therapies (such as a clinical pharmacist, dietitian or psychologist) to help them reach an informed decision.

The lead clinician should assure patients who use complementary or alternative therapies that they can still access multidisciplinary team reviews (NBCC & NCCI 2003) and encourage full disclosure about therapies being used (Cancer Australia 2010).

Further information

- See Cancer Australia's position statement on complementary and alternative therapies at <<http://canceraustralia.gov.au/publications-and-resources/position-statements/complementary-and-alternative-therapies>>.
- See the Clinical Oncology Society of Australia's position statement available at <www.cosa.org.au/publications/position-statements.aspx>.

4.6 Support and communication

4.6.1 Supportive care

Screening with a validated screening tool (such as the National Comprehensive Cancer Network Distress Thermometer and Problem Checklist), assessment and referral to appropriate health professionals and/or organisations is required to meet the needs of individual patients, their families and carers.

Supportive care needs

In addition to the common issues outlined in the **appendix**, specific needs that may arise at this time include the following.

Physical needs

- Provide support for neurological impairment and seizure control.
- Information about seizures should be provided to the family and carers. This information should cover what to expect and what to do in the event of a seizure, such as maintaining the person's airway and removing dangerous objects from the area. This may help relieve the anxiety of family and carers.
- Headaches can be severe, and specific management by the medical specialist is generally required.
- Corticosteroids are commonly used with benefit. Because they are given in high doses over prolonged periods, significant side effects are likely. Treat with the lowest effective dose. Patients should know who to contact in case of emergency.
- Fatigue/change in functional abilities is a common symptom, and patients may benefit from referral to occupational therapy.
- Focal deficits may affect the patient's mobility and ability to take part in everyday activities. Referral to an occupational therapist and a physiotherapist for assessment, education, intervention and compensatory strategies may assist with maintaining mobility.
- Dysphasia may occur, and referral to a speech pathologist may be needed (Taillibert et al. 2004).
- Decline in mobility and/or functional status may result from treatment.
- Assistance with managing complex medication regimens, multiple medications, assessment of side effects and assistance with difficulties swallowing medications may be required. Refer to a pharmacist if necessary.

Psychological needs

- Patients may need support with emotional and psychological issues including, but not limited to, body image concerns, fatigue, existential anxiety, treatment phobias, anxiety/depression, interpersonal problems and sexuality concerns.

Cognitive dysfunction and personality and behavioural changes

- Alteration in cognitive functioning, behaviour and personality are common with gliomas and are often unrecognised but can impact significantly on normal activities. Ongoing assessment and management from neuropsychologists, neuropsychiatrists or occupational therapy should be considered if feasible (Australian Cancer Network 2009).

Social/practical needs

- Ensure the patient attends appointments.
- Potential isolation from normal support networks, particularly for rural patients who are staying away from home for treatment, and for patients with neuropsychiatric symptoms can be an issue. Social isolation can also compound distress (Australian Cancer Network 2009).
- Financial issues related to loss of income and additional expenses as a result of illness and/or treatment may require support.
- Help with legal issues may be required including advance care planning, appointing a power of attorney and completing a will.

Information needs

- Provide appropriate information to patients and carers about how to manage alterations in cognitive function and potential changes in behaviour.
- Give advice about safe driving.
- Provide appropriate information for people from culturally and linguistically diverse backgrounds.

Spiritual needs

- Multidisciplinary teams should have access to suitably qualified, authorised and appointed spiritual caregivers who can act as a resource for patients, carers and staff.
- Patients with cancer and their families should have access to spiritual support appropriate to their needs throughout the cancer journey.

4.6.2 Communication with the patient, family and carer

The lead clinician should:

- offer advice to patients and carers on the benefits of or how to access support from brain cancer peer support groups, groups for carers and special interest groups (visit <www.btaa.org.au>)
- discuss the treatment plan with the patient and carer, including the intent of treatment and expected outcomes (provide a written plan after final histopathological diagnosis (not frozen section) is available)
- provide the patient and carer with information on possible side effects of treatment, self-management strategies and emergency contacts
- provide information about seizures to the family and carers (this information should cover what to expect and what to do in the event of a seizure, such as maintaining the person's airway and removing dangerous objects from the area; this may help relieve the anxiety of family and carers)
- recognise the ability of the patient and carers to comprehend the communication
- provide appropriate information to the person's carer regarding managing altered cognitive function and/or behaviour (when there are significant cognitive impairments, carers are likely to assume a central role in communication and decision making (Australian Cancer Network 2009))
- provide information regarding safe mobility to carers as well as patients
- initiate a discussion regarding advance care planning with the patient and carer.

4.6.3 Communication with the general practitioner

The lead clinician should:

- communicate with the person's general practitioner their role in symptom management, psychosocial care and referral to local services
- ensure regular and timely two-way communication regarding
 - the treatment plan, including intent and potential side effects
 - supportive and palliative care requirements
 - the patient's prognosis and their understanding of this
 - enrolment in research and/or clinical trials
 - changes in treatment or medications
 - recommendations from the multidisciplinary team.

Step 5: Care after initial treatment and recovery

The transition from active treatment to post-treatment care is critical to long-term health. After completing their initial treatment, patients should be provided with a treatment summary and follow-up care plan including a comprehensive list of issues identified by all members of the multidisciplinary team. Transition from acute to primary or community care will vary depending on the type and stage of cancer and needs to be planned. In some cases, people will require ongoing, hospital-based care.

5.1 Survivorship

High-grade glioma has a poor prognosis with a high recurrence rate. The majority of high-grade glioma patients have incurable disease, but longer term survivors exist. Patients should be managed within the multidisciplinary team framework. Early referral to a palliative care specialist is recommended at disease progression (Philip et al. 2013b).

Patients with high-grade glioma experience persistent side effects at the end of treatment. Physical, emotional and psychological issues include distress, anxiety, depression, cognitive changes and fear of cancer recurrence. Patients may experience altered relationships and may encounter practical issues including difficulties with return to work or study, and financial hardship.

Patients may be discharged into the community and generally need to see a specialist for regular followup appointments. The Institute of Medicine, in its report *From cancer patient to cancer survivor: Lost in transition*, describes four essential components of survivorship care (Hewitt et al. 2006):

- the prevention of recurrent and new cancers, as well as late effects
- surveillance for cancer spread, recurrence or second cancers, and screening and assessment for medical and psychosocial late effects
- interventions to deal with the consequences of cancer and cancer treatments (including management of symptoms, distress and practical issues)
- coordination of care between all providers to ensure the patient's needs are met.

All patients should be educated in managing their own health needs (NCSI 2015).

5.2 Post-treatment care planning

5.2.1 Treatment summary

After initial treatment, the patient, the patient's nominated carer (as appropriate) and general practitioner should receive a 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.

5.2.2 Follow-up care

Care in the post-treatment phase is driven by predicted risks (such as the risk of recurrence, developing late effects and psychological issues), as well as individual clinical and supportive care needs.

Responsibility for follow-up care should be agreed between the lead clinician, the general practitioner, relevant members of the multidisciplinary team and the patient, with an agreed plan that outlines:

- what medical follow-up is required (surveillance for recurrence, screening and assessment for medical and psychosocial effects)
- care plans from other health professionals to manage the consequences of cancer and treatment
- a process for rapid re-entry to specialist medical services for suspected recurrence
- the role of follow-up for patients, which is to evaluate tumour control, monitor and manage symptoms from the tumour and treatment and provide psychological support
- that they will be retained within the multidisciplinary team management framework
- the arrangements for follow-up with the neurosurgeon for a postoperative evaluation, which should occur four to eight weeks after surgery.

Follow-up consists of a clinical evaluation, with particular attention to neurological function, seizures and corticosteroid use.

Surveillance should include:

- regular radiological assessment with MRI
- access to a range of health professions (if required) including physiotherapy, occupational therapy, nursing, social work, dietetics, neuro-psychology and palliative care.

5.3 Research and clinical trials

All patients with a high-grade glioma should be offered the opportunity to participate in a clinical trial or clinical research if appropriate (Field et al. 2013).

Cross-referral between clinical trials centres should be encouraged to facilitate participation.

- Cooperative Trials Group for Neuro-oncology (COGNO) coordinates large-scale multi-centred neuro-oncology trials. For more information visit <www.cogno.org.au>.
- Australian Cancer Trials is a national clinical trials database. It provides information on the latest clinical trials in cancer care, including trials that are recruiting new participants. For more information visit <www.australiancancertrials.gov.au>.

5.4 Support and communication

5.4.1 Supportive care

Screening using a validated screening tool and referral to appropriate health professionals and community-based support services is required to meet the needs of individual patients, their families and carers.

Supportive care needs

In addition to the other common issues outlined in the **appendix**, specific needs that may arise at this time include the following.

Physical needs

- Provide support for neurological impairment and seizure control.
- Headaches can be severe, and specific management by the medical specialist is generally required.
- Corticosteroids are commonly used with benefit. Because they are given in high doses over prolonged periods, significant side effects are likely. Treat with the lowest effective dose. Patients should know who to contact in case of emergency.
- Fatigue/change in functional abilities is a common symptom, and patients may benefit from referral to occupational therapy.
- Focal deficits may affect the patient's mobility and ability to take part in everyday activities. Referral to an occupational therapist and a physiotherapist for assessment, education, intervention and compensatory strategies may assist with maintaining mobility.
- Dysphasia may occur, and referral to a speech pathologist may be needed (Taillibert et al. 2004).
- Because there is an increased potential for deep vein thrombosis and pulmonary embolism with high-grade gliomas, patients and their carers need to be alerted to possible symptoms and advised what to do (Junck 2004).
- Decline in mobility and/or functional status may result from treatment.

Psychological needs

- Behavioural changes or dementia, particularly in patients treated with postoperative irradiation, may occur.
- Patients may need support with emotional and psychological issues including, but not limited to, body image concerns, fatigue, existential anxiety, treatment phobias, anxiety/depression, interpersonal problems and sexuality concerns.

Cognitive dysfunction and personality and behavioural changes

- Alteration in cognitive functioning, behaviour and personality are common with gliomas and are often unrecognised but can impact significantly on normal activities. Ongoing assessment and management from neuropsychologists, neuropsychiatrists or occupational therapy should be considered if feasible (Australian Cancer Network 2009).

Social/practical needs

- Ensure the patient attends appointments.
- Potential isolation from normal support networks, particularly for rural patients who are staying away from home for treatment, and for patients with neuropsychiatric symptoms is often an issue. Social isolation can also compound distress (Australian Cancer Network 2009).
- Financial issues related to loss of income and additional expenses as a result of illness and/or treatment may require support.
- Provide support with legal issues (including advance care planning, appointing a power of attorney and completing a will).

Information needs

- Provide appropriate information to patients and carers about how to manage alterations in cognitive function and potential changes in behaviour.
- Give advice about safe driving.
- Provide appropriate information for people from culturally and linguistically diverse backgrounds.

Spiritual needs

- Multidisciplinary teams should have access to suitably qualified, authorised and appointed spiritual caregivers who can act as a resource for patients, carers and staff.
- Patients with cancer and their families should have access to spiritual support appropriate to their needs throughout the cancer journey.

5.4.2 Rehabilitation and recovery

Rehabilitation may be required at any point of the care pathway.

Issues that may need to be addressed include managing fatigue, falls, cognitive changes, improving physical endurance, achieving independence in daily tasks, returning to work and ongoing adjustment to disease and its sequelae.

Return to driving may require occupational therapy/rehabilitation assessment with reference to the Australian guidelines, which are available at <<http://www.austroads.com.au/drivers-vehicles/assessing-fitness-to-drive>>.

5.4.3 Palliative care

Given the poor prognosis of this cancer at present, for the majority of patients, treatment is often given with palliative rather than curative intent. Specialist palliative care will be required for patients with high-grade glioma.

The lead clinician should ensure patients receive timely and appropriate referral to palliative care services. Referral should be based on need rather than prognosis.

- Patients may be referred to palliative care at initial diagnosis.
- Patients should be referred to palliative care at first recurrence or progression.
- Carer needs may prompt referral (Collins et al. 2013).

Early referral to palliative care can improve the quality of life for people with cancer (Haines 2011; Temel et al. 2010; Zimmermann et al. 2014). This is particularly true for poor-prognosis cancers (Philip et al. 2013b; Cancer Council Australia 2012; Temel et al. 2010). Furthermore, palliative care has been associated with the improved wellbeing of carers (Higginson 2010; Hudson et al. 2014).

Ensure carers and families receive information, support and guidance regarding their role according to their needs and wishes (Palliative Care Australia 2005).

The patient and carer should be encouraged to develop an advance care plan (AHMAC 2011).

Further information

Refer patients and carers to Palliative Care Australia at <www.palliativecare.org.au>.

5.4.4 Communication with the patient, carer and family

The lead clinician should:

- offer advice to patients and carers on the benefits of or how to access support from brain cancer peer support groups, groups for carers and special interest groups
- explain the treatment summary and follow-up care plan
- provide information about the signs and symptoms of recurrent disease
- provide information about healthy living.

When there are significant cognitive impairments, information about safe mobility needs to be made available to carers as well as patients.

5.4.5 Communication with the general practitioner

The lead clinician should ensure regular, timely, two-way communication with the patient's general practitioner regarding:

- the follow-up care plan
- potential late effects
- supportive and palliative care requirements
- the patient's progress
- recommendations from the multidisciplinary team
- any shared care arrangements.

Step 6: Managing recurrent or progressive disease

Step 6 is concerned with managing recurrent or progressive disease.

The pathway and management of patients with recurrent or progressive glioma is a continuum of care within the multidisciplinary team and recapitulates section 4.

With the low rates of curable high-grade glioma and the majority of patients palliated, it is likely that their current symptoms will worsen progressively, and this should be managed following discussion at a multidisciplinary clinic in consultation with palliative care specialists.

The supportive care needs of these patients are particularly important and should be reassessed. Palliative care referral and linkages and increased support within the community and general practitioner involvement are also particularly important.

Recurrence is very common for patients with high-grade glioma. Management will vary but may include further surgery, radiation therapy or systemic therapies. Patients should be managed in the context of the multidisciplinary team framework. Patients should be referred to palliative care specialists early at this stage of disease.

Step 7: End-of-life care

End-of-life care is appropriate when the patient's symptoms are increasing and functional status is declining. Step 7 is concerned with maintaining the patient's quality of life and addressing their health and supportive care needs as they approach the end of life, as well as the needs of their family and carer. Consideration of appropriate venues of care is essential. The principles of a palliative approach to care need to be shared by the team when making decisions with the patient and their family.

7.1 Multidisciplinary palliative care

If not already underway, referral to palliative care should be considered at this stage (including nursing, pastoral care, palliative medicine specialist backup, inpatient palliative bed access as required, social work, neuro-psychology/psychiatry and bereavement counselling), with general practitioner engagement.

If not already in place, the patient and carer should be encouraged to develop an advance care plan (AHMAC 2011).

The palliative care team may consider seeking additional expertise from a:

- pain service
- pastoral carer or spiritual advisor
- bereavement counsellor
- therapist (for example, music or art).

The team might also recommend accessing:

- respite specialist
- home- and community-based care
- specialist community palliative care workers
- community nursing.

Consideration of an appropriate place of care and preferred place of death is essential.

Occupational therapy home assessment is also essential to ensure the safe management of palliative patients receiving home-based care.

Ensure carers and families receive information, support and guidance regarding their role according to their needs and wishes (Palliative Care Australia 2005).

Further information

Refer patients and carers to Palliative Care Australia at <www.palliativecare.org.au>.

7.2 Research and clinical trials

All patients with a high-grade glioma should be offered the opportunity to participate in a clinical trial or clinical research if appropriate (Field et al. 2013).

Cross-referral between clinical trials centres should be encouraged to facilitate participation.

- Cooperative Trials Group for Neuro-oncology (COGNO) coordinates large-scale multi-centred neuro-oncology trials. For more information visit <www.cogno.org.au>.
- Australian Cancer Trials is a national clinical trials database. It provides information on the latest clinical trials in cancer care, including trials that are recruiting new participants. For more information visit <www.australiancancertrials.gov.au>.

7.3 Support and communication

7.3.1 Supportive care

Screening, assessment and referral to appropriate health professionals is required to meet the identified needs of an individual, their carer and family.

Supportive care needs

In addition to the other common issues outlined in the **appendix**, specific needs that may arise at this time include the following.

Physical needs

- Provide support for neurological impairment and seizure control.
- Focal deficits may affect the patient's mobility and ability to take part in everyday activities. Referral to an occupational therapist and a physiotherapist for assessment, education, intervention and compensatory strategies may assist with maintaining mobility.
- Other physical symptoms such as pain and fatigue may require extra support.
- Decline in mobility and/or functional status impacting on the patient's discharge destination will need to be considered.
- Headaches can be severe, and specific management by the medical specialist is generally required.
- Fatigue/change in functional abilities is a common symptom, and patients may benefit from referral to occupational therapy.

Psychological needs

- Patients, carers and families may need strategies to deal with emotional and psychological distress from anticipatory grief, fear of death/dying, anxiety/depression, interpersonal problems and anticipatory bereavement support.
- Patients who experience existential distress may benefit from supportive psychotherapy.

Cognitive dysfunction and personality and behavioural changes

- Behavioural changes or dementia can be severe, and specific management by a neuro-psychologist/psychiatrist is generally required during this stage of disease progression.

Social/practical needs

- Provide support for the practical, financial and emotional impacts on carers and family members resulting from the increased care needs of the patient.
- Offer specific support for families where a parent is dying and will leave behind bereaved children or adolescents, creating special family needs.
- Ensure the patient attends appointments.
- Potential isolation from normal support networks, particularly for rural patients who are staying away from home for treatment and for patients with neuropsychiatric symptoms is often an issue. Social isolation can also compound distress (Australian Cancer Network 2009).
- Provide support for financial issues related to loss of income and additional expenses as a result of the illness and/or treatment.
- Offer support regarding legal issues including advance care planning, appointing a power of attorney and completing a will.

Information needs

- Provide information for patients and families about arranging a funeral.
- Communicate about the death and dying process and what to expect.
- Communicate with all members of the care team that the patient has died.
- Provide appropriate information for people from culturally and linguistically diverse backgrounds.

Spiritual needs

- Cater to specific spiritual needs that may benefit from the involvement of pastoral care.
- Provide bereavement support for family and friends.
- Multidisciplinary teams should have access to suitably qualified, authorised and appointed spiritual caregivers who can act as a resource for patients, carers and staff.
- Patients with cancer and their families should have access to spiritual support appropriate to their needs throughout the cancer journey.

Communication with the patient, carer and family

The lead clinician should:

- be open to and encourage discussion about the expected disease course, with due consideration to personal and cultural beliefs and expectations
- discuss palliative care options including inpatient and community-based services as well as dying at home and subsequent arrangements
- provide the patient and carer with the contact details of a palliative care service.

7.3.3 Communication with the general practitioner

The lead clinician should discuss end-of-life care planning and transition planning to ensure the patient's needs and goals are addressed in the appropriate environment. The patient's general practitioner should be kept fully informed and involved in major developments in the patient's illness trajectory.

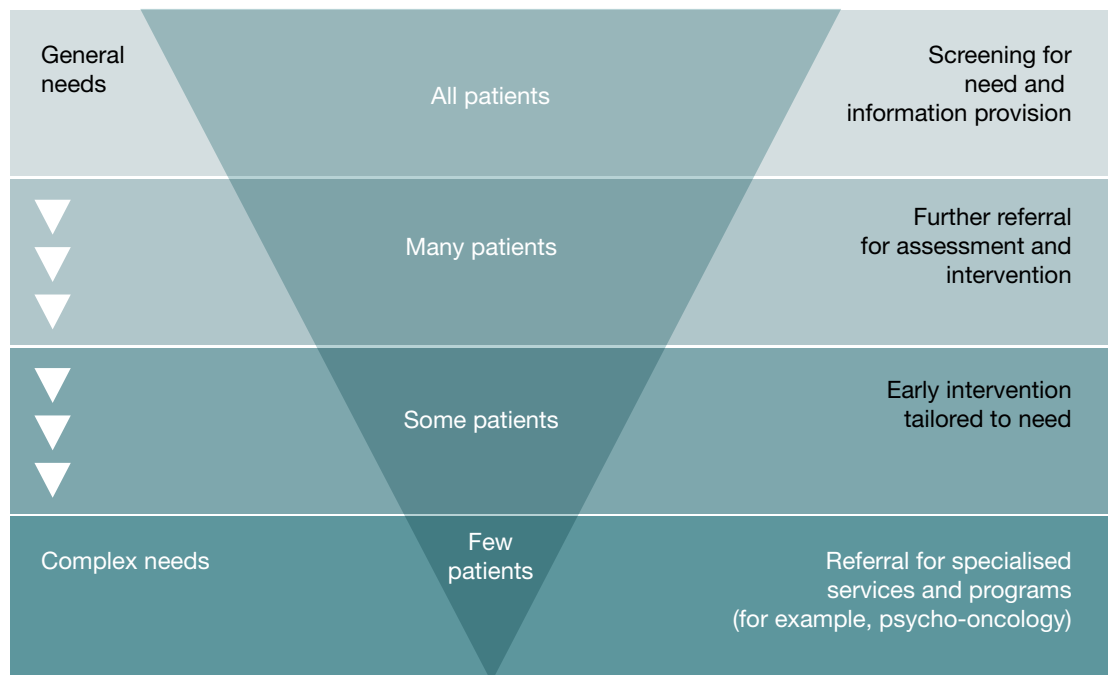
Appendix: Supportive care

Supportive care in cancer refers to the following five domains:

- physical domain, which includes a wide range of physical symptoms that may be acute, relatively short-lived or ongoing, requiring continuing interventions or rehabilitation (NBCC & NCCI 2003)
- psychological domain, which includes a range of issues related to the person's mental health and personal relationships (NBCC & NCCI 2003)
- social domain, which includes a range of social and practical issues that will impact on the individual and their family such as the need for emotional support, maintaining social networks and financial concerns (NICE 2004)
- information domain, which includes access to information about cancer and its treatment, support services and the health system overall (NBCC & NCCI 2003)
- spiritual domain, which focuses on the person's changing sense of self and challenges to their underlying beliefs and existential concerns (NICE 2004).

Fitch's (2000) model of supportive care (Figure 1) recognises the variety and level of intervention required at each critical point as well as the need to be specific to the individual. The model targets the type and level of intervention required to meet patients' supportive care needs.

Figure 1: The tiered approach



The majority of high-grade glioma patients will require specialised intervention (thus an inverted pyramid is more applicable for this cohort of cancer patients). Common indicators in patients with high-grade glioma who may require referral to appropriate health professionals and/or organisations include the following.

Physical needs

- Physical decline is common in patients with high-grade glioma. Maintenance of function should be encouraged. Referral to a physiotherapist should be considered if further advice is required.
- Provide support for neurological impairment and seizure control.
- Headaches can be severe, and specific management by the medical specialist is generally required.
- Corticosteroids are commonly used with benefit. Because they are given in high doses over prolonged periods, significant side effects are likely. Treat with the lowest effective dose. Patients should know who to contact in case of emergency.
- Fatigue/change in functional capacity is a common symptom, and patients may benefit from referral to occupational therapy.
- Focal deficits may affect the patient's mobility and ability to take part in everyday activities. Referral to an occupational therapist and a physiotherapist for assessment, education, intervention and compensatory strategies may assist with maintaining mobility.
- Dysphasia may occur, and referral to a speech pathologist may be needed (Taillibert et al. 2004).
- Because there is an increased potential for deep vein thrombosis and pulmonary embolism with high-grade gliomas, patients and their carers need to be alerted to possible symptoms and advised what to do (Junck 2004).

Psychological needs

- For some populations (culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islanders, and lesbian, gay, bisexual, transgender and intersex (LGBTI) communities) a cancer diagnosis can come with additional psycho-social complexities. Access to expert health professionals who possess knowledge specific to the psychosocial needs of these groups may be required.
- Patients with high-grade glioma should be regularly screened for depression and anxiety as a result of increased dependency. If loss of independence is a factor contributing to depression, then referral to physiotherapy and occupational therapy may restore some independence and assist some people. Referral to a psychologist or psychiatrist may also be helpful in managing the depression.
- Fear of cancer recurrence is reported to be extremely common in the post-treatment phase. Some people may have disabling symptoms and may benefit from referral to a psychology service.
- Distress and depression can be just as common in carers and family members, including children.
- Behavioural changes or dementia, particularly in patients treated with postoperative irradiation, may require specific support.
- Neurocognitive effects related to the tumour and its treatment are often an issue. Cognitive dysfunction is common and often unrecognised and patients and their families/carers may benefit from appropriate management. It is important to ask carers about symptoms that may be related to cognitive dysfunction.

- Alteration in cognitive functioning can affect the patient's ability to remember and maintain concentration. Strategies to help manage cognitive impairment, such as maintaining written notes, diary and so on, may be helpful.
- Patients may need support with emotional and psychological issues including, but not limited to, body image concerns, fatigue, existential anxiety, treatment phobias, anxiety/depression, interpersonal problems and sexuality concerns.
- Consider a referral to a psychologist, psychiatrist or social worker if the patient is:
 - displaying emotional cues such as tearfulness, distress, avoidance and withdrawal
 - preoccupied with or dwelling on thoughts about cancer and death
 - displaying fears about the treatment process and/or the changed goals of their treatment
 - worried about loss associated with their daily function, dependence on others and loss of dignity
 - becoming isolated from family and friends and withdrawing from company and activities that they previously enjoyed
 - feeling hopeless and helpless about the impact that brain cancer is having on their life and the disruption to their life plans
 - struggling with communicating to family and loved ones about the implications of their cancer diagnosis and treatment
 - experiencing changes in sexual intimacy, libido and function
 - struggling with the diagnosis of metastatic or advanced disease
 - having difficulties transitioning to palliative care.

Social/practical needs

- A diagnosis of high-grade glioma can have significant financial, social and practical impacts on patients, carers and families. Brain tumours cause the highest economic burden on Australian cancer patients' households, with an average cost estimated to be more than five times higher than for breast or prostate cancer patients (Australian Cancer Network 2009).
- The additional costs related to equipment to assist with mobility, physiotherapy review for exercise assistance to maximise mobility, inability or reduced capacity to work and respite care are significant. A referral to a social worker should be considered for further assessment and identification of financial and practical support available.
- Significant restrictions to social activities may require referral to a social worker, occupational therapist, psychologist or psychiatrist.
- Provide advice about safe driving.
- Consider the need for appropriate information for people from culturally and linguistically diverse backgrounds.

Spiritual needs

- Multidisciplinary teams should have access to suitably qualified, authorised and appointed spiritual caregivers who can act as a resource for patients, carers and staff. They should also have up-to-date awareness of local community resources for spiritual care.
- Patients with cancer and their families should have access to spiritual support appropriate to their needs throughout the cancer journey.

Populations with special needs

Older people with cancer (aged 70 years or older)

Planning and delivering appropriate cancer care for older people presents a number of challenges. Improved communication between the fields of oncology and geriatrics is required to facilitate the delivery of best practice care, which takes into account physiological age, complex comorbidities, risk of adverse events and drug interactions, as well as implications of cognitive impairment on suitability of treatment and consent (Steer et al. 2009).

A national interdisciplinary workshop convened by the Clinical Oncology Society of Australia (COSA) recommended that people over the age of 70 undergo some form of geriatric assessment in line with international guidelines (COSA 2013). Assessment can be used to determine life expectancy and treatment tolerance as well as identifying conditions that might interfere with treatment including:

- function
- comorbidity
- presence of geriatric syndromes
- nutrition
- polypharmacy
- cognition
- emotional status
- social supports.

Paediatrics

The rarity and complexity of child cancer provides a real challenge in delivering optimal care. Treatment modalities for paediatric cancer are often prolonged and complicated and have a narrow therapeutic index. Side effects of systemic therapy for treating cancer can be more severe for children, including acute organ toxicities, prolonged immunodeficiency and infection.

As a result of these complexities, high-quality evidence-based care is required not only to deliver therapy and supportive care but is essential in the diagnosis phase, post-treatment surveillance and long-term follow-up care. Children with cancer should be managed by specialised paediatric services under a 'shared care' model to ensure a critical mass. These specialised services work with others to enable the provision of supportive care closer to home when it is safe to do so. Children's cancer services actively participate in clinical trials as a way of participating in research and improving outcomes for children.

Evidence shows that best outcomes demand a well-coordinated, timely, multidisciplinary approach requiring effective collaboration of health services working together as a team (Children's Oncology Group 2012; Corrigan & Fieg 2004). Integrated care is fundamental to paediatric cancer care and service delivery.

Adolescents and young adults

Recent years have seen the emergence of adolescent and young adult (AYA) oncology as a distinct field due to lack of progress in survival and quality-of-life outcomes (Ferrari et al. 2010; NCI & USDHHS 2006; Smith et al. 2013). The significant developmental change that occurs during this life stage complicates a diagnosis of cancer during the AYA years, often leading to unique physical, social and emotional impacts for young people at the time of diagnosis and throughout the cancer journey (Smith et al. 2012).

In caring for young people with cancer, careful attention to the promotion of normal development is required (COSA 2011). This requires personalised assessments and management involving a multidisciplinary, disease-specific, developmentally targeted approach informed by:

- understanding the developmental stages of adolescence and supporting normal adolescent health and development alongside cancer management
- understanding and supporting the rights of young people
- communication skills and information delivery that are appropriate to the young person
- addressing the needs of all involved, including the young person, their family and/or carer(s)
- working with educational institutions and workplaces
- addressing survivorship and palliative care needs.

An oncology team caring for a young person with cancer must:

- ensure access to expert AYA health professionals who possess knowledge specific to the biomedical and psychosocial needs of the population
- understand the biology and current management of the disease in the AYA age group
- consider clinical trials accessibility and recruitment for each patient
- engage in proactive discussions about fertility preservation and the late effects of treatment and consider the patient's psychosocial needs
- provide treatment in an AYA-friendly environment.

Aboriginal and Torres Strait Islander communities

The burden of cancer is higher in the Australian Indigenous population (AIHW 2014). Survival also significantly decreases as remoteness increases, unlike the survivorship rates of non-Indigenous Australians. Aboriginal and Torres Strait Islander people in Australia have high rates of certain lifestyle risk factors including tobacco smoking, higher alcohol consumption, poor diet and low levels of physical activity (Cancer Australia 2013). The high prevalence of these risk factors is believed to be a significant contributing factor to the patterns of cancer incidence and mortality rates in this population group (Robotin et al. 2008).

In caring for Aboriginal and Torres Strait Islander people diagnosed with cancer, the current gap in survivorship is a significant issue. The following approaches are recommended to improve survivorship outcomes (Cancer Australia 2013):

- Raise awareness of risk factors and deliver key cancer messages.
- Develop evidence-based information and resources for community and health professionals.
- Provide training for Aboriginal and Torres Strait Islander health workers and develop training resources.
- Increase understanding of barriers to care and support.
- Encourage and fund research.
- Improve knowledge within the community to act on cancer risk and symptoms.
- Improve the capacity of Aboriginal and Torres Strait Islander health workers to provide cancer care and support to their communities.
- Improve system responsiveness to cultural needs.
- Improve our understanding of care gaps through data monitoring and targeted priority research.

Culturally and linguistically diverse communities

For people from diverse backgrounds in Australia, a cancer diagnosis can come with additional complexities, particularly when English proficiency is poor. In some languages there is not a direct translation of the word 'cancer', which can make communicating vital information difficult. Perceptions of cancer and related issues can differ greatly in those from culturally diverse backgrounds and can impact on the understanding and decision making that follows a cancer diagnosis. In addition to different cultural beliefs, when English language skills are limited there is potential for miscommunication of important information and advice, which can lead to increased stress and anxiety for patients. A professionally trained interpreter (not a family member or friend) should be made available when communicating with people with limited English proficiency. Navigation of the Australian healthcare system can pose problems for those born overseas, and particular attention should be paid to supporting these patients (Department of Health 2009).

Resource list

For patients, families and carers

American Brain Tumor Association

Provides support and resources for brain tumour patients and caregivers

- <www.abta.org>

Australian Cancer Survivorship Centre

Has general and tumour-specific information, primarily focused on the post-treatment survivorship phase

- Telephone: (03) 9656 5207
- <www.petermac.org/cancersurvivorship>

beyondblue

Information on depression, anxiety and related disorders, available treatment and support services

- Telephone: 1300 22 4636
- <www.beyondblue.org.au>

The Brain Foundation

A charity funding world-class research Australia-wide into neurological disorders, brain disease and brain injuries

- <<http://brainfoundation.org.au>>

The Brain Tumour Alliance Australia

Information resources and support for newly diagnosed patients and their families

- Telephone: 1800 857 221
(free call number for peer support)
- <www.btaa.org.au>

Cancer Australia

Information on cancer prevention, screening, diagnosis, treatment and supportive care for Australians affected by cancer, and their families and carers

- Telephone: 1800 624 973
- <www.canceraustralia.gov.au>

Cancer Council (operated by Cancer Council Victoria)

A confidential telephone support service for people affected by cancer providing information on treatment, cancer support groups and other community resources

- Telephone: 13 11 20
(Monday to Friday, 8.30 am – 5.30 pm)
- <www.cancervic.org.au>

Cancer Voices Australia

An alliance of cancer consumer organisations that works together on national issues for people affected by cancer

- <www.cancervoicesaustralia.org>

Care Search: Palliative Care Knowledge Network

Information for patients and carers on living with illness, practical advice on how to care and finding services

- Telephone: (08) 7221 8233
- <www.caresearch.com.au>

For health professionals

Australian Cancer Trials

Information on the latest clinical trials in cancer care, including trials that are recruiting new participants

- <www.australiancancertrials.gov.au>

Cancer Australia

Information for health professionals including guidelines, cancer guides, reports, fact sheets, DVDs, posters and pamphlets

- <www.canceraustralia.gov.au>

Cancer Council Australia

Information on prevention, research, treatment and support provided by Australia's peak independent cancer authority

- <www.cancer.org.au>

COGNO

Cooperative Trials Group for Neuro-oncology (COGNO) coordinates the management of large-scale multi-centred neuro-oncology trials

- <www.cogno.org.au>

eviQ

Clinical information resource providing health professionals with current evidence-based, peer maintained, best practice cancer treatment protocols and information relevant to the Australian clinical environment

- <www.eviq.org.au>

National Health and Medical Research Council

Information on clinical practice guidelines, cancer prevention and treatment

- <www.nhmrc.gov.au>

Primary brain tumour module

An online learning module for specialist cancer nurses caring for people affected by primary brain tumours

- <<http://brainmodule.cancerinstitute.org.au>>

Glossary

Advance care planning – a process of discussing future medical treatment and care based on an individual's preferences, goals, beliefs and values, which can guide future decisions should the person become unable to communicate.

Alternative therapies – treatments that are used in place of conventional medical treatment, often in the hope they will provide a cure.

Care coordinator – the health professional nominated by the multidisciplinary team to coordinate patient care. The care coordinator may change over time depending on the patient's stage in the care pathway and where care is primarily located.

Complementary therapies – supportive treatment used in conjunction with conventional medical treatment. These treatments may improve wellbeing and quality of life and help people deal with the side effects of cancer.

End-of-life care – a distinct phase of palliative care that is appropriate when a patient's symptoms are increasing and functional status is declining despite anti-cancer therapy.

General/primary medical practitioner – the practitioner to whom the patient first presents with symptoms; this may be the general practitioner, an emergency department clinician or a medical professional providing cancer screening services.

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.

Multidisciplinary care – an integrated team approach to healthcare in which medical and allied health professionals consider all relevant treatment options and develop an individual treatment plan collaboratively for each patient (Department of Health 2007b).

Multidisciplinary team – comprises the core disciplines integral to providing good care. The team is flexible in approach, reflects the patient's clinical and psychosocial needs and has processes to facilitate good communication.

Optimal cancer care pathway – the key principles and practices required at each stage of the care pathway to guide the delivery of consistent, safe, high-quality and evidence-based care.

Palliative care – any form of medical care or treatment that concentrates on reducing the severity of disease symptoms.

Patient management frameworks – tumour stream models adopted in Victoria in 2003 to reduce variation in cancer care. The optimal cancer care pathways are updated versions of these models.

Primary specialist – the person who makes the referral to the multidisciplinary team (for example, specialist physician, surgeon, oncologist, palliative care specialist). This person will also make referrals for treatment and will be responsible for overseeing follow-up care.

Rehabilitation – comprises multidisciplinary efforts to allow the patient to achieve optimal physical, social, physiological and vocational functioning within the limits imposed by the disease and its treatment.

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Ms Luisa Barassi, Nurse and Brain Tumour Research Coordinator, Melbourne Health
Dr Lawrence Cher, Neuro-oncologist, Epworth Hospital, Austin Health
Ms Emma Daly, Neuro-oncology Clinical Nurse Consultant, Cabrini Health
Professor Gavin Davis, Neurosurgeon, Austin Health, Cabrini Health
Dr Anthony Dowling, Medical Oncologist, St Vincent's Hospital
Associate Professor Kate Drummond, Neurosurgeon, Melbourne Health
Mrs Marilyn Dolling, consumer representative, OCP Steering Committee, Cancer Action Victoria
Dr Ronnie Freilich, Neuro-oncologist, Cabrini Health, Monash Health
Dr Frank Gaillard, Neuroradiologist, Melbourne Health
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Dr Zarnie Lwin, Medical Oncologist, Senior Lecturer, Royal Brisbane and Women's Hospital, The University of Queensland
Associate Professor Jennifer Philip, Deputy Director of Palliative Medicine, St Vincent's Hospital
Ms Jan Quiney, Senior Clinician Physiotherapist, Neuroscience Centre, Melbourne Health
Ms Jane Staker, Neuro-Oncology Nurse Coordinator, St Vincent's Hospital
Professor Robert Thomas, Chief Advisor on Cancer, Department of Health & Human Services

Alexandra Philpott, Project Manager – Optimal Cancer Care Pathways

Governance – project steering committee representation

Ballarat Health Services
Cancer Australia
Cancer Council Victoria, Strategy and Support
Consumer representatives
Department of Health & Human Services, Cancer Strategy and Development
Grampians Integrated Cancer Service
Monash University
North Eastern Melbourne Integrated Cancer Service
Peter MacCallum Cancer Centre
Royal Hobart Hospital
Western Health

Medical colleges and peak organisations invited to provide feedback

Allied Health Professions Australia
Australian Association of Nuclear Medicine Specialists
Australian and New Zealand Society of Palliative Care
Australian Chapter of Palliative Medicine, Royal Australasian College of Physicians
Australian College of Nursing
Australian Institute of Radiography
Australian Medical Association
Brain Tumour Alliance Australia
Cooperative Trials Group for Neuro-Oncology
Medical Oncology Group of Australia
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Royal Australian and New Zealand College of Radiologists
Royal Australian College of General Practitioners

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