


Patient management framework

# Central nervous system tumour stream: malignant glioma



a guide to  
**consistent**  
cancer care



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## Acknowledgements

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## 1. Introduction

Cancer is the leading cause of death in Victoria, representing 28.9 per cent of all deaths in 2002<sup>27</sup>. Population ageing will significantly increase the number of new cases of cancer over the next ten years, with an estimated 10,000 more cases per annum in Victoria by 2016. In 2003, 346 Victorians were diagnosed with brain and central nervous system tumours and in 2002, there were 341 deaths due to tumours of the brain and central nervous system<sup>27</sup>.

Cancer is a complex disease to diagnose and treat, and represents a significant burden to patients and their families, the health system, and the community at large. Victoria's strategic and planned approach to cancer reform includes the establishment of a Ministerial Taskforce for Cancer, and implementation of the *Fighting cancer policy*<sup>2</sup> and *A cancer services framework for Victoria*<sup>28</sup>. Two significant directions of the Cancer Services Framework are the establishment of integrated cancer services in metropolitan and regional Victoria, and the development of service delivery and improvement through a tumour streams model.

Since 2004, eight integrated cancer services have been established in metropolitan and regional Victoria, based on specified geographic populations. The philosophy of an integrated cancer service is that hospitals and primary and community health services develop integrated care and defined referral pathways for the populations they serve. This requires effective collaboration between hospitals and community-based services, including general practitioners. This will promote more effective local coordination of care for cancer patients, and a more rational, evidence-based approach to cancer service planning and delivery. The Cancer Services Framework also recommended that organ or system-specific tumour streams be adopted to support the delivery and improvement of care. The reasoning behind the tumour streams is that a consistent approach to clinical management based on evidence-based practice will reduce unacceptable variations in care across the state.

## 2. Patient management frameworks

The Cancer Services Framework suggested some areas for improvement in the quality of care for cancer patients in Victoria. These included:

- under-treatment of patients with colorectal, lung and prostate cancer<sup>10,24,25</sup>
- inadequate follow-up surveillance of patients with testicular cancer<sup>29</sup>
- a high proportion of cancer patients undergoing surgery with surgeons who performed relatively few operations for colorectal cancer<sup>25,12</sup>
- a high proportion of surgery for ovarian cancer having been undertaken by generalists rather than specialist surgical oncologists<sup>11</sup>.

As a consequence, the Cancer Services Framework recommended that tumour streams be developed to reduce unwanted variation in practice. In response, the Ministerial Taskforce for Cancer recommended that patient management frameworks be developed to provide a consistent statewide approach to care management in each tumour stream. The patient management frameworks are a clear description of the care pathway, identifying the critical points along that pathway and the optimal model of care required. It is important that all patients are assessed and managed appropriately throughout each stage of their journey; however, it should be noted that not all patients will progress through each step of the relevant patient management framework. This is a consequence of many factors, including disease outcomes, management decisions, and patient decisions.

### 2.1 Purpose of the patient management frameworks

The patient management frameworks **are a guide** to the **optimal care management** of patients in each tumour stream. They are intended to improve patient outcomes by facilitating consistent care based on evidence and best practice across the state. They set out the key requirements for the provision of optimal care which need to be considered at each step of the care pathway. In contrast to clinical practice guidelines that guide appropriate practice and decision making, the patient management frameworks provide a guide to the patient journey to ensure patients with cancer and their families receive optimal care and support.

As a guide, the patient management frameworks are to be followed subject to the health professional's independent medical judgment and the patient's preference in each individual case. They are designed to provide information to assist in decision making and organisation of service delivery.

The patient management frameworks **are not rules** and **do not carry a sense of prescription**. The patient management frameworks represent the 'what', rather than seeking to prescribe the 'how'. Recognising that services should be responsive to the needs of different patients at different phases, the patient management frameworks draw on best practice and encourage local solutions. For example, while multidisciplinary care is an essential part of treatment planning, how it is organised depends on the local situation.

In their current format, the patient management frameworks are not designed for accreditation purposes, but may be used to facilitate local benchmarking, service mapping and service development.

The patient management frameworks have been developed in collaboration with a wide range of practitioners, consumers and carers. Wherever possible, the patient management frameworks are based on current best practice, including clinical guidelines, care pathways, standards and research that exist to support optimal care at the critical points. In many cases, however, they are a statement of consensus regarding currently accepted approaches to treatment.

## 2.2 Structure of the patient management frameworks

The patient management frameworks set out seven critical steps of the patient journey. The seven steps provide a consistent structure across the ten tumour streams. While the seven steps appear as a linear model, it is clear that in practice patient care does not always occur in this way but rather depends on the particular cancer, when and how the cancer is diagnosed, prognosis, management decisions, and patient decisions.

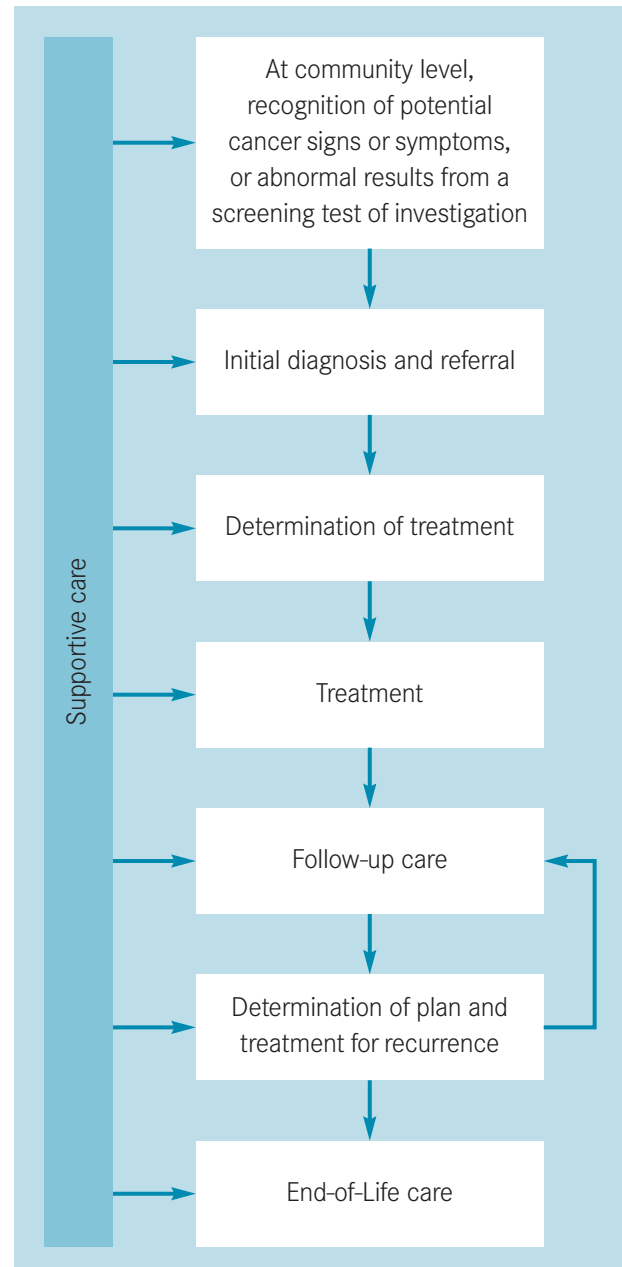
Underpinning the patient management frameworks are key principles that support all seven steps. These are:

**1. patient-centred care.** Patients should be involved as active participants in care planning and decision making, and wherever appropriate so should their partners, families and carers. Ultimately, any treatment decision rests with the patient or designated person. This requires information and discussion in their preferred language and sensitive to their culture

**2. safe and high quality care.** Cancer care is complex, involving a range of clinicians with different expertise. To ensure safe and high quality cancer care, it is important that clinicians have the technical skills and experience to carry out those aspects of cancer care they undertake and that there is institutional capacity to support such care, such as equipment, staffing and skill mix. Further detail is provided in section 3

**3. multidisciplinary care.** The cornerstone of best practice in cancer care is multidisciplinary treatment planning and multidisciplinary care. An effective multidisciplinary approach can result in survival benefit<sup>15</sup>, increased recruitment into clinical trials<sup>17,18</sup> detection of emotional needs of patients<sup>4</sup>, reduction in service duplication and improved coordination of services<sup>3</sup>. Further detail is provided in section 4

Figure 1: Steps of the patient journey



**4. supportive care.** People with cancer have psychological and social needs that are frequently undetected and unmet<sup>20</sup>. This has the potential to result in long term distress. In the context of cancer, supportive care describes all services that may be required to support people with cancer and their carers to meet their physical, psychological, social, information and spiritual needs. Further detail is provided in section 5

**5. care coordination.** The cancer journey is complex and challenging, and it is not uncommon for patients to be seen by many health professionals within and across multiple health services and across different sectors. A variety of strategies are successful in improving the coordination of care. Some of these include strategies directed at the team, such as multidisciplinary team meetings, clinical protocols and case conferencing; strategies directed at the patient, such as personal patient records, appropriate information provision or case managers; and strategies directed at the health care system, such as electronic medical records, standards, performance indicators and funding models. To ensure patients experience care that is coordinated and integrated over time and settings, services need to consider the range of strategies required to facilitate care coordination.

## 2.3 Development of the patient management frameworks

The patient management frameworks have been developed over a 15-month period in consultation with more than 500 clinicians and consumers through workshops and written submissions. Further information on the development process can be obtained at <http://www.health.vic.gov.au/cancer/tumourstreams.htm>.

Fourteen patient management frameworks have been developed, addressing the following tumour streams and tumour categories:

- breast
- central nervous system (cerebral metastases)
- central nervous system (malignant glioma)
- colorectal (colon and rectal)
- genitourinary (prostate)
- genitourinary (testis)
- gynaecological (ovarian)
- haematological (acute myeloid leukaemia)
- haematological (intermediate grade non-hodgkin's lymphoma)
- head and neck (larynx, pharynx and oral)
- lung (non-small cell)
- skin (melanoma)
- upper gastrointestinal (oesophagogastric)
- upper gastrointestinal (pancreatic).

## 2.4 Future review and development of the patient management frameworks

The 14 patient management frameworks that have been developed will be reviewed in December 2007. Further development of patient management frameworks relevant to the ten major tumour streams will commence in January 2007.

### 3. Credentialling and scope of practice

In 2004, the *National standard for credentialling and defining the scope of clinical practice*<sup>1</sup> was endorsed by the Australian Health Ministers. Developed by the Australian Council for Safety and Quality in Health Care, the standard provides a credentialling framework for all medical practitioners. Credentialling is a formal process for verifying qualifications, competence and performance of individual clinicians as well as defining their scope of practice within a specific health service. The process takes into account the skills and ability of the clinician as well as the capacity of the institution to support the clinician's practice.

This has particular relevance to clinicians working in the area of cancer care. Cancer care is complex for a number of reasons. These include:

- the large number and type of cancers that vary greatly in their pathology and management
- the range of clinicians with different professional expertise (medicine, nursing, allied health) that are involved in care
- the range of specialities for specific treatment modalities, such as breast or colorectal surgeons, radiation and medical oncologists, breast care nurses
- the life-threatening nature of many cancers and the serious complications and side-effects of some treatments
- the advances in technology and research that are changing best practice care at a rapid pace<sup>9</sup>.

In Victoria, the complexity of cancer care poses specific challenges for health professionals working in the area of cancer. The large distances between health services and the relatively low numbers of complex cancers that will be seen at individual health services or by individual health professionals require that innovative approaches to care be developed. These include developing links between health professionals and multidisciplinary teams and initiatives such as the expansion of telemedicine, specific mentoring and upskilling programs.

For patients to have access to safe and high quality services, it is important that professionals working in the area of cancer care ensure:

- they have the necessary skills to carry out those aspects of cancer care they undertake and there is institutional capacity to support such care (for example, equipment, staffing and skill mix)
- they have clear links with a range of specialties or multidisciplinary care team required for cancer care, for the purpose of clinical advice, referral and continuing education
- they follow evidence-based practice or treatment recommendations of a multidisciplinary care team
- they undertake regular review of their performance and contribute to regular audit of their cancer care
- they are actively involved in continuing professional development
- their patients can make an informed choice about their care, including the options of referral to other professionals or specialised centres<sup>9</sup>.

## 4. Multidisciplinary care

### 4.1 Achieving multidisciplinary care

Multidisciplinary care is an approach that includes both treatment planning and ongoing care. The 'gold standard' for multidisciplinary care is a team who meets regularly (whether in person or via teleconferencing) to prospectively plan care and treatment for all patients within a tumour group; however, it is expected that different components of multidisciplinary care will be implemented depending on the setting, the location of the team and the number and type of cancer patients being treated. While it may not always be possible to hold a multidisciplinary team meeting prior to surgery, for instance, it would be expected that some other form of multidisciplinary discussion around treatment planning take place. It is likely that regional multidisciplinary care will look different from metropolitan, while being guided by the principle that interaction between multidisciplinary team members is critical in the determination and effective implementation of the treatment plan. It is also acknowledged that patients move between the private and public sector and multidisciplinary care needs to take this into account.

### 4.2 Principles of multidisciplinary care<sup>19</sup>

#### The team

- There is an established multidisciplinary team comprising all core disciplines, including allied health and psychosocial health practitioners.
- The patient's general practitioner is regarded as a team member and processes to ensure effective communication with general practitioners are implemented.
- Effective communication and referral linkages are made to all core and non-core team members.

#### Communication

- All core disciplines where appropriate and relevant regularly attend multidisciplinary meetings to provide input to diagnostic, treatment, supportive and palliative care planning.

- In instances where not all patients within a tumour group or groups are discussed, team protocols are developed to outline those patients who will be presented at meetings.
- Processes for communicating treatment and care plans for team members who are absent are developed and implemented.

#### Full therapeutic range

- All patients regardless of where they reside will have information about and access to relevant treatments and services.
- Clinical trial involvement is considered for all eligible patients who will be undergoing cancer treatment.

#### Quality

- Decisions, protocols and care pathways are in line with current best practice, including standards, guidelines, research and where these are not available, currently accepted approaches to treatment.
- All relevant diagnostic results, reports and pathology and radiology images are available for multidisciplinary meetings.
- Collaborative links will be formed with smaller and larger referring centres and practitioners. The result will be a network of multidisciplinary teams and practitioners across and between integrated cancer services.
- Professional development activities are supported and held for all team members.

#### Involvement of patient

- Patients are informed of the multidisciplinary team process.
- Patients are informed of the recommendations of the multidisciplinary discussion, provided with information about all aspects of their treatment and participate in the decision making process.
- Patients are routinely given information about and access to supportive care services.

## 5. Supportive care

‘Supportive care is an ‘umbrella’ term for all services, both generalist and specialist, that may be required to support people with cancer and their carers’<sup>21</sup>. It includes self-help and support, information, psychological support, symptom control, social support, rehabilitation, spiritual support, palliative care and bereavement care<sup>21</sup>.

Supportive care is required throughout the diagnostic, treatment and follow-up phases of care<sup>7</sup>.

In the context of cancer, supportive care needs include:

- physical needs (for example, pain, fatigue)
- psychological needs (for example, anxiety, distress)
- social needs (for example, practical supports, carer needs)
- information needs (for example, regarding diagnosis, prognosis, types of treatment)
- spiritual needs (for example, addressing hopelessness, despair).

### 5.1 Providers of supportive care

Supportive care is provided by generalist and specialist health services as well as community services.

All members of the multidisciplinary team, including general practitioner, surgeon, radiation oncologist, medical oncologist, nurse, social worker and other allied health staff, have a role in the provision of supportive care. In addition, community capacity to support people with cancer makes an important contribution to supportive care. This includes support from family, friends, support groups, volunteers and other community-based organisations.

As a specialist service, palliative care may provide many of the elements of supportive care; however, palliative care also includes specific areas of expertise that may be required, such as unresolved symptoms, and complex psychosocial, end-of-life and bereavement issues<sup>21</sup>.

### 5.2 Achieving supportive care

An important step in the provision of supportive care services is to identify, by routine and systematic questioning of the patient and family, views on issues they require help with for optimal health and quality of life outcomes<sup>8</sup>. Reassessment of their needs is not a ‘once only’ incident because a person’s needs change along the disease trajectory<sup>13</sup>.

A routine and systematic approach to identifying supportive care needs will help to identify people who are at higher risk of psychological or social distress. This identification provides the opportunity for further referral for assessment that is specific to their needs and recognises the individual factors that may place them at increased risk of psychological morbidity. Such factors include characteristics of the individual, such as age and marital status, and characteristics of the disease, such as time of diagnosis or recurrence, stage of disease and prognosis<sup>20</sup>.

A detailed assessment will help to identify those patients who require more specific one-to-one intervention and follow-up.

### 5.3 Establishing a supportive care model

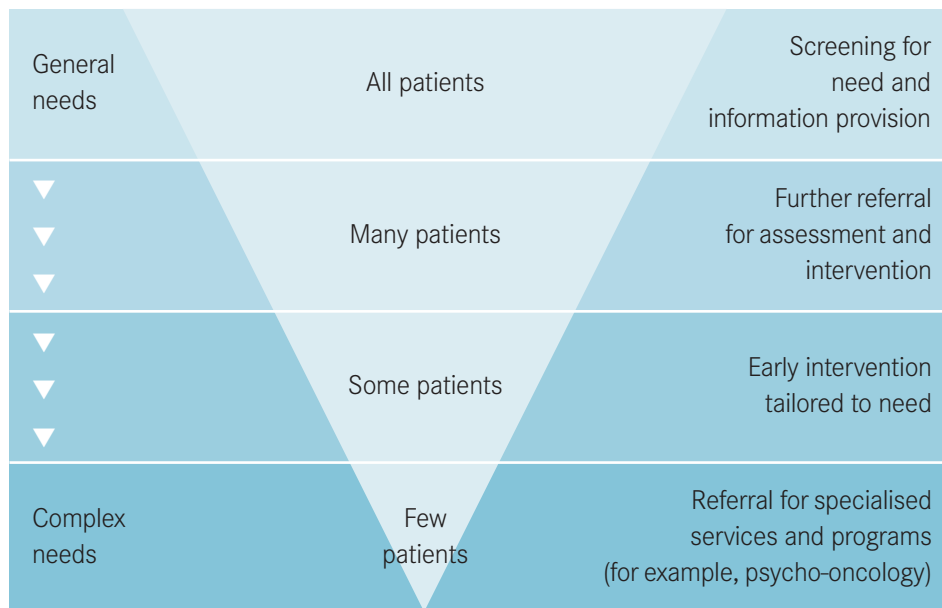
A supportive care model should recognise the variety and the level of intervention required at each phase and be specific to the individual. Such a model (see Figure 2) targets the type and level of intervention required to meet patients' supportive care needs. While there needs to be provision of general information to all patients, only a few patients will require specialised intervention.

As supportive care is provided by a range of services, it is important the following are considered in ensuring cancer patients have access to supportive care:

- processes that assist the identification of patient, family and carer supportive care needs
- clear referral pathways to specialised supportive care services
- adequate staff training in identifying and responding to supportive care needs
- promotion of supportive care as an important element of cancer service delivery.

**Figure 2: Supportive care model**

(Adapted from Fitch<sup>7</sup>. Reproduced with kind permission of Peter MacCallum Cancer Centre).



## 6. Steps in the care of patients with malignant glioma

This section sets out the steps along the treatment pathway and the optimal care required. Not all patients will follow every step of the pathway. This will depend on the stage of the cancer at diagnosis and the patient's decisions about his or her care.

### Step 1:

#### At community level, recognition of potential cancer signs or symptoms, or abnormal results from a screening test or investigation

*This step identifies screening programs, the types of people who may be at higher than average risk of developing cancer, and the types of symptoms that require further investigation by the general practitioner.*

##### 1.1 Screening

- There are no screening programs for malignant glioma.

##### 1.2 Those at higher risk

- There are no identified risk factors for glioma.

##### 1.3 Signs and symptoms that should lead to general practitioner consultation

- While symptoms are often non-specific, the following should be investigated:
  - increasing headaches, persistent new headaches, vomiting
  - seizure, twitching, unusual movements, blackouts
  - poor coordination
  - visual deterioration
  - progressive weakness
  - confusion, behaviour changes, poor memory, drowsiness
  - speech disturbance.

Note: While investigation of non-specific symptoms such as headache (for example, with CT scan) is low yield, it is nevertheless indicated.

##### 1.4 Timeframe for general practitioner consultation

- For significant symptoms, the patient should be seen within 24 hours.
- For milder non-specific symptoms, the patient should be seen within days or weeks.

## Step 2: Initial diagnosis and referral

*This step details the process for establishing the diagnosis and appropriate referral. The types of investigations undertaken by the general practitioner and specialist (neurologist or neurosurgeon) depend on many factors, such as the patient's desires, access to particular tests or access to specialists. Decisions on investigations require discussion and agreement between the general practitioner, specialist and patient.*

### 2.1 General practitioner

- General practitioner examinations/investigations should include:
  - history and neurological examination
  - brain CT scan, with and without contrast, within 24 hours of request. Urgency of scan depends on the clinical scenario and the practitioner's assessment of the seriousness of clinical status.

Note: The quality of CT scan is a frequent problem; the scan must be with and without contrast.
- CT results should be received within the same 24 hours. Where the result is positive, the radiologist should contact the general practitioner immediately.
- Prior discussion with specialist is not necessary, but is useful for sick patients or those who have had seizures.
- The doctor of first contact needs to tell the patient there is an abnormality on the scan and emphasise the importance of a prompt specialist appointment.
- The patient should not drive until neurosurgical review.
- CT is inadequate for a small number of patients. Where CT is negative but there is continuing clinical concern, specialist referral and/or MRI should be performed. Where there are persistent neurological symptoms, the patient should be referred to a specialist.

### 2.2 Referral

- The patient should be referred to a neurologist or neurosurgeon who works in an environment able to undertake ongoing care in a multidisciplinary brain tumour team.
- The patient should be personally referred (usually by direct discussion) by the doctor of first contact to the neurosurgeon or neurosurgery registrar. The appointment should be confirmed within 24 hours. Information with the referral should include the abnormal scan and a request for urgent assessment.
- Imaging should accompany the patient to neurological/neurosurgical review, with referral letter.
- The specialist should provide timely communication to the general practitioner about the consultation, and should notify the general practitioner if the patient does not attend.

### 2.3 Staging

- Staging is the cornerstone of treatment planning.
- CT scan and MRI are required for staging.
- Tissue diagnosis occurs following surgery.

### Step 3: Determination of treatment

*This step identifies the members of the multidisciplinary team who need to be involved in initial treatment planning for this type of cancer. While the planning process varies considerably depending on the type of the cancer and the context of the care, the guiding principle is that interaction between appropriate multidisciplinary team members should determine the treatment plan.*

#### 3.1 Multidisciplinary team

- The multidisciplinary team comprises (in alphabetical order):
  - general practitioner
  - medical oncologist or neuro-oncologist
  - neurologist
  - neuropathologist
  - neuroradiologist
  - neurosurgeon
  - nurse
  - palliative care service
  - radiation oncologist
  - social worker
- with access to:
  - allied health services where appropriate (physiotherapy, speech pathology, occupational therapy, dietitian and pharmacist)
  - psycho-oncology services where appropriate (psychologist/psychiatrist).
- Leader of the team should be:
  - before surgery: the neurosurgeon
  - post-operatively: the neurosurgeon or neuro-oncologist.

#### 3.2 Multidisciplinary planning

- In general, involvement of the multidisciplinary team should occur immediately after tissue diagnosis.
- For certain tumour subgroups (brainstem glioma, eloquent area, multiple tumours, unusual tumours), involvement of the multidisciplinary team should occur before surgery.
- The primary specialist who makes the referral to the multidisciplinary team is responsible for the patient until care is passed to another practitioner.

### 3.3 Next steps in starting treatment

- Surgery and tissue diagnosis should be by the neurosurgeon.
- Post-operative MRI within 48 hours of surgery is desirable if resection is performed.
- Diagnosis and recommended treatment plan should be discussed with the patient and/or family in a family meeting, by the neurosurgeon with other support as required. This should include the rationale and aim of treatment, likely effects, possible outcomes, other options, and psychosocial supports for patient and family. This should not occur until final histopathological diagnosis (not frozen section) is available.
- A number of meetings may be necessary to involve other members of the team after the diagnosis/plan has been communicated and to clarify information.
- There should be timely communication (before hospital discharge) to the general practitioner about the tissue diagnosis and the agreed treatment plan. This should be done via telephone and discharge summary.
- The patient should be referred to the radiation oncologist and medical oncologist while in hospital and preferably seen by them while in hospital. Definite follow-up appointments should be confirmed.
- Patients having early discharge, before tissue diagnosis, require early outpatient review by all three specialties.
- Progression of care within the multidisciplinary team should be coordinated, ensuring the patient, general practitioner and multidisciplinary team members are clear on their responsibilities for coordination of care.

## Step 4: Treatment

*This step is concerned with the scope of clinical practice to deliver quality and safe practice. Scope of practice reflects both the expertise and experience of the individual as well as the organisational capability for the provision of safe, high quality cancer services<sup>1</sup>.*

### 4A: Surgery

#### 4A.1 Patients who may benefit from surgery

- All patients should be considered for surgery by a neurosurgeon in consultation with the patient and family.

#### 4A.2 Training and experience of surgeon

- Neurosurgeon (FRACS or equivalent) with adequate training and experience that enables institutional credentialling and agreed scope of practice within this area<sup>1</sup>

#### 4A.3 Hospital or treatment unit characteristics

##### **Staff**

Staffing includes:

- multidisciplinary team as detailed in 3.1
- surgeon as specified in 4A.2
- neurosurgical anaesthetic services.

##### **Facilities**

The following are available:

- full neurosurgical service for cranial neurosurgery with MRI, post-operative high dependency and intensive care unit facilities, neuroradiologist and neuropathologist
- transport provision for patients. This is very important because the distance to travel to appropriate services may be significant, especially for patients with a disability.

### 4B: Radiotherapy

#### 4B.1 Patients who may benefit from radiotherapy

- All patients should be considered for radiotherapy and/or concomitant chemotherapy.

#### 4B.2 Training and experience of radiation oncologist

- Radiation oncologist (FRANZCR or equivalent) with adequate training and experience that enables institutional credentialling and agreed scope of practice within this area<sup>1</sup>

#### 4B.3 Hospital or treatment unit characteristics

##### **Staff**

Staffing includes:

- nurses
- radiation oncologist as specified in 4B.2
- radiation oncology medical physicist
- radiation therapist.

### **Facilities**

The following are available:

- ability to treat patients within three weeks of surgery<sup>6</sup>
- dual modality LINACS
- CT planning facilities
- treatment planning system.

## **4C: Drug therapy**

### **4C.1 Patients who may benefit from drug therapy**

- A multidisciplinary team should consider all patients for chemotherapy.

### **4C.2 Training and experience of medical oncologist**

- Medical oncologist or neuro-oncologist (FRACP or equivalent) with adequate training and experience that enables institutional credentialling and agreed scope of practice within this area<sup>1</sup>

### **4C.3 Hospital or treatment unit characteristics**

#### **Staff**

Staffing includes:

- medical oncologist as specified in 4C.2
- nurses with adequate training in chemotherapy administration, handling and disposal of cytotoxic waste
- If chemotherapy is prepared on site, then a pharmacist with adequate training in chemotherapy medications, including dosing calculations according to protocols, formulations and/or preparation is required.
- Some components of less complex therapies may be delivered in a setting where no medical oncologist is locally available, by another medical practitioner with training and experience that enables credentialling and agreed scope of practice within this area. 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.

#### **Facilities**

- The facility has a clearly defined path to emergency care and advice after hours.
- The facility is able to care for neutropenic patients.
- There is access to haematology testing.
- Cytotoxic drugs are prepared in a pharmacy with appropriate facilities.
- Occupational health and safety guidelines are followed in relation to handling of cytotoxic drugs, including preparation, waste procedures and spill kits<sup>30</sup>.
- Guidelines and protocols, in the case of extravasation of drugs are available and understood.
- Treatment can be given in smaller centres but should always be in collaboration with the medical oncologist and/or the multidisciplinary team.

## Step 5: Follow-up care

*This step includes monitoring of the status of the disease (including detection of recurrent or persistent disease) and management of symptoms that arise following the initial treatment. A clear follow-up plan needs to be established to avoid excessive follow-up by multiple specialists. Follow-up may vary depending on the intent of the initial treatment.*

### 5.1 Plan for follow-up

- Follow-up by the neurosurgeon should occur four to nine weeks after surgery.
- MRI should be performed generally one to three months after radiotherapy, depending on when radiotherapy commences and clinical circumstances; then at three- to six-month intervals, depending on clinical circumstances and subsequent deterioration.
- The patient should be followed up by the nominated specialist after each scan as a minimum, and sometimes more frequently.
- Follow-up by the radiation oncologist is variable, but patients are usually discharged from radiation oncology care after radiotherapy.
- Anticonvulsant use should be reviewed by the neurologist or neuro-oncologist, particularly if there are ongoing seizures. Anticonvulsant levels should be regularly monitored and cessation of therapy considered.
- The general practitioner needs to know the general management plan as well as information about every hospital visit, specialist appointment and results of recent tests.

### 5.2 Persons involved in follow-up care

- Not all disciplines need to be involved in longer term follow-up. The lead clinician (neurosurgeon or medical oncologist) needs to be in charge of follow-up, with involvement of other multidisciplinary team members as appropriate.
- The general practitioner has a key role in coordination of follow-up and in managing day-to-day issues.
- Psychologist, neuro-psychologist or psychiatrist, as well as the rehabilitation team, have important roles in this stage.
- For rural patients, some aspects of care can be provided locally (oncology, district nurse by liaison with multidisciplinary team), but neurosurgical follow-up is generally centralised.
- Responsibility for follow-up investigations needs to be agreed between the lead clinician, the general practitioner and the patient, with an agreed plan documented, including notification to the general practitioner or multidisciplinary team member if the patient does not attend.

## **Step 6:**

### **Determination of plan and treatment for recurrence**

*This step covers treatment for recurrence. The intent is disease control and, in some situations, palliative. Clinical evaluation and patient decision making will determine the focus of the treatment.*

#### **6.1 Investigative tests and appropriate referrals**

- Symptoms suggestive of recurrence should be investigated with MRI.

#### **6.2 Multidisciplinary team**

- Management should be discussed by a multidisciplinary team that includes (in alphabetical order):
  - general practitioner
  - medical oncologist or neuro-oncologist
  - neurologist
  - neuropathologist
  - neuroradiologist
  - neurosurgeon
  - nurse
  - palliative care service
  - radiation oncologist
  - rehabilitation team, including physiotherapist, occupational therapist and speech pathologist if required
  - social worker.

General practitioner and palliative care service participation is essential.

#### **6.3 Treatments that a patient is most likely to have for recurrence**

Treatment will depend on the location and extent of the recurrence, and on previous management. Treatment may include surgery, radiotherapy and/or drug therapy.

## Step 7: End-of-life care

*This step is concerned with quality of life for the patient and his or her family through care that addresses physical, psychological, emotional and spiritual needs. For the family and carers, this may include bereavement support.*

### 7.1 Multidisciplinary team

- The multidisciplinary team should include (in alphabetical order):
  - allied health staff as appropriate
  - nurses
  - general practitioner
  - palliative care service—relevant team members
  - medical oncologist
  - radiation oncologist for symptom management
  - pastoral care services—relevant team members.

Note: Medical oncology or palliative care specialist may be primary team, depending on previous care/relationship.

### 7.2 Services that may be required

- Palliative care service: community-based and inpatient. Care needs to include consideration of special needs relating to neurological impairment and seizure control.
- Home and community care
- Community nursing
- Allied health: dietitian, occupational therapy, pastoral care, physiotherapy, speech pathology
- Access to oncology unit

## 7. Specific supportive care needs to consider for patients with malignant glioma

The supportive care needs of patients with malignant glioma will vary in severity and complexity along the disease trajectory. Identifying and assessing the supportive care needs of people with malignant glioma involves a general assessment of the physical, psychological, social, information and spiritual needs as detailed in section 5. In addition to these general needs, all members of the multidisciplinary team should be aware of the particular needs related to malignant glioma detailed below which may require intervention from specific members of the multidisciplinary team.

### Physical needs

- Headaches<sup>26</sup> can be severe and specific management by the medical specialist is generally required. Other techniques, such as relaxation therapy, distraction and massage, may have short term effects in relieving pain<sup>16</sup>.
- Information about seizures<sup>26</sup> 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 maintain airway and remove dangerous objects from the area. This may help relieve the anxiety of family and carers.
- Focal deficits<sup>26</sup> may affect the patient's mobility and ability to attend activities of daily living. Review and possible referral to an occupational therapist and a physiotherapist for equipment and exercises to assist with maintaining mobility may be required.
- Alteration in cognitive functioning<sup>5,26</sup> can affect the patient's ability to remember and maintain concentration<sup>23</sup>. Strategies to help manage cognitive impairment, such as maintaining written notes, diary and so on, may be helpful.
- Patients taking high dose steroids need to be aware of the possibility of weight gain, cushingoid appearance and myopathy related to steroids<sup>14</sup>, and the effects of changes need to be monitored and doses reviewed in light of benefits.

- Because there is an increased potential for deep vein thrombosis and pulmonary embolism with high grade gliomas<sup>14</sup>, patients and their carers need to be alerted to possible symptoms and advised what to do.
- Aphasia<sup>26</sup> may occur and referral to a speech pathologist may be needed.
- Physical impairment can affect mobility and other activities of daily living. Rehabilitation, including physiotherapy and occupational therapy, is usually required.

### Psychological needs

#### Distress

- A poor prognosis<sup>23</sup> and concern about future<sup>26</sup> may cause distress for patients and carers. Sensitive discussion about these concerns, and possible referral to palliative care services, social worker, psychologist and/or psychiatrist, may be required.

#### Depression

- The incidence of depression ranges from 5 per cent to 95 per cent in this group<sup>22</sup> and can be a result of increased dependency<sup>26</sup>. Clinicians should regularly screen patients with malignant glioma for signs of depression. 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.

#### Self-esteem

- Changes in appearance and loss of independence can result in low self-esteem<sup>26</sup>. Referral to physiotherapy and occupational therapy may restore some independence with movement and therefore assist with self-esteem. Referral to a psychologist or psychiatrist may also help with self-esteem.

## Social/practical needs

- 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. Referral to a social worker for further assessment and identification of appropriate funding support is necessary.

## Information needs

- Cognitive impairment may affect the ability to retain information and therefore require varied methods of information provision as well as frequent repeating of information. Carers and family members require information about cognitive impairments and advice about what to do.
- When there are significant cognitive impairments, information about safe mobility needs to be made available to carers as well as patients.
- Further specific information is available from The Cancer Council Victoria web site <http://www.cancervic.org.au/cancer1/patients/brain/tellmore.htm>.

## 8. Resource list

### For patients, families and carers

#### 1. The Cancer Council Victoria

1 Rathdowne Street  
Carlton 3053

Telephone: 03 9635 5000  
Facsimile: 03 9635 5270  
Email: enquiries@cancervic.org.au  
Web site: <http://www.cancer.org.au>

For information on cancer, its treatment and side effects, support services, medical terminology, and research

#### 2. Cancer Helpline (operated by The Cancer Council Victoria)

Telephone: 13 11 20  
Hours: Monday to Friday, 8.30 am–5.30 pm

For telephone peer support from people who have had cancer experiences or for information on more than 120 cancer support groups across Victoria

#### 3. The Cancer Council Australia

<http://www.cancer.org.au>

##### *Fact sheets:*

Lifestyle: [www.cancer.org.au/lifestyle](http://www.cancer.org.au/lifestyle)  
Early detection: [www.cancer.org.au/earlydetection](http://www.cancer.org.au/earlydetection)  
Post diagnosis: [www.cancer.org.au/diagnosis](http://www.cancer.org.au/diagnosis)

### For health professionals

#### 4. National Health and Medical Research Council

<http://www.nhmrc.gov.au/publications/subjects/cancer.htm>

For downloading clinical practice guidelines for cancer prevention and treatment

#### 5. The Cancer Council Australia

*Fact sheets for health professionals providing advice to patients:*

<http://www.cancer.org.au/factsheets>

One-page fact sheets to help general practitioners and other health professionals advise their patients about cancer prevention, screening and diagnosis. These can also be downloaded from the patient education browser in the latest version (2.86) of the general practice software package, Medical Director.

*Cancer resources for primary health care professionals:*  
[www.cancer.org.au/primarycare](http://www.cancer.org.au/primarycare)

Directory of cancer resources to support general practitioners and other health professionals. Developed by the General Practice Committee of The Cancer Council Australia, the directory provides a single point of access to state, territory and national cancer resources.

#### 6. Clinical trials

A national, online register of clinical trials being undertaken in Australia, the Australian Clinical Trials Registry, is available at <http://www.actr.org.au>. The Australian Clinical Trials Registry includes trials from the full spectrum of therapeutic areas, trials of pharmaceuticals, surgical procedures, preventive measures, lifestyle, devices, treatment and rehabilitation strategies and complementary therapies.

## 9. Abbreviations

CT	computed tomography
FRACP	Fellow of Royal Australasian College of Physicians
FRACS	Fellow of Royal Australasian College of Surgeons
FRANZCR	Fellow of Royal Australian and New Zealand College of Radiologists
LINAC	linear accelerator
MRI	magnetic resonance imaging

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