Model for Neuro-Oncology Cancer
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1. Introduction

Cancer is the leading cause of death in Western Australia, representing 30.6 per cent of all deaths in 2006.¹

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 Western Australia by 2016. In 2006, 141 Western Australians were diagnosed with neurological (brain, meninges and spinal cord) cancer. Of these 134 were brain tumours, the majority of which were gliomas. There were 101 deaths due to neurological cancer in 2006, of which 98 occurred in patients with brain tumours.²

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.

Western Australia’s strategic and planned approach to cancer reform includes the establishment of a Ministerial Taskforce for Cancer, the implementation of the Fighting cancer policy and a cancer services framework for Western Australia.³

Two significant directions of the Cancer Services Framework are the establishment of integrated cancer services in metropolitan and regional Western Australia, 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 Western Australia 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.

Data Collection and Audit

Data collection regarding treatment and outcomes is essential to monitor the quality and safety of care. An appropriate clinical database for neuro-oncology cancer treatment and outcomes should be available and adequately resourced. Treatment outcomes including morbidity and survival data should be readily available in the public domain.
Model of Care


This document describes how Neuro-Oncology Cancer care should be delivered in WA.

The eight steps in figure 1 describe the patient centred journey that provides safe, quality, evidence based, and multidisciplinary care resulting in optimum outcomes.

Underpinning this journey is the integration of primary care, supportive care, psycho-oncology and palliative care.

Every cancer patient should have appropriate access to specialist cancer care

- Prevention & Screening
- Symptomatic Presentation
- Initial Diagnosis & Referral
- Diagnostic Pathways (Fast Track / Staging)
- MDT Assessment & Plan of Treatment
- Treatment
- Surveillance (follow up care)
- Survivorship (long-term survival uncommon)
- Relapse & Retreatment
- Palliative Care
2. Screening & Prevention

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.

2.1 Screening

- There are no screening programs for malignant neurological tumours.

However, there needs to be support for ongoing research into the causes of neurological cancer and identification of high risk individuals who may potentially benefit from screening.

2.2 Those at Higher Risk

- Ionizing radiation and immunosuppression are risk factors for neurological malignancy but satisfactory screening programs are yet to be developed.

2.3 Prevention

- In the absence of other identified risk factors there are currently no strategies for prevention in the general population.
3. 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 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. Clinical management for most common tumour (Glioma) will be in accordance with the newly developed Draft Clinical Practice guidelines for the management of adult gliomas.

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 where the symptom is new, persistent, or accompanied by other symptoms of neurological cancers.

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.

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.

Access for general practitioners to guidelines for appropriate referral, and education on referral, investigation and assessment of patients with a suspected brain tumour, needs to be readily available.

Referral

- The patient should be referred to a 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 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.

Systems need to be in place to ensure fast tracking of suspected cancer patients for diagnostic purposes. Use of designated referral lines should be considered.

Diagnosis

- Accurate histological diagnosis is the cornerstone of treatment planning.
- CT scan and MRI are required.
- Tissue diagnosis occurs following surgery.
4. MDT Assessment and Plan 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.

Multidisciplinary Team

The multidisciplinary team comprises (in alphabetical order):

- cancer nurse coordinator
- medical oncologist
- neuropathologist
- neuroradiologist
- neurosurgeon
- nurse practitioner
- palliative care service
- radiation oncologist

With access to:

- general practitioner
- allied health services where appropriate (physiotherapy, speech pathology, occupational therapy, dietician, social worker and pharmacist). It is recognised that allied health practitioners are an integral part of the MDT and may receive and initiate referrals.
- psycho-oncology services where appropriate (clinical psychologist/psychiatrist), preferably at initial MDT assessment if resources allow.

The lead role in the multidisciplinary team will be determined by the team and must take responsibility for the activity of the team.

Multidisciplinary Planning

Objectives of a multidisciplinary team meeting (MDT) are:

1. Confirm staging
2. Determine treatment plan
3. Document the MDT recommendations
4. Convey the recommendations to the referring neurosurgeon or physician and primary care provider

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 may be required before surgery.

- All patients, public and private, with a neurological cancer should be discussed in a multidisciplinary team meeting.
- Results of all relevant tests and imaging must be available for the multidisciplinary team discussion.
The primary specialist who makes the referral to the multidisciplinary team is responsible for the patient until care is passed to another practitioner.

The recommendations of the MDT regarding the treatment plan should be clearly documented and circulated to all members of the MDT shortly after the meeting.

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.

The patient, and (with the patient’s consent) the family, should be involved in all discussions regarding the treatment options recommended by the MDT. It is not anticipated that this would occur at the time of the MDT.

**Next steps in starting treatment**

- Surgery should be undertaken by the neurosurgeon, and tissue histopathological diagnosis by a specialist neuropathologist.
- Ideally Intra-operative and/or 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.
- Prior to discharge from hospital all relevant specialist appointments should be in place and both the patient and the general practitioner be informed.
- 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 to the general practitioner about the tissue diagnosis and the agreed treatment plan. This should be done via telephone and discharge summary.
- Multi-modality treatment is common and the patient should be referred to the radiation oncologist, medical oncologist and cancer nurse coordinator 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 in a multidisciplinary setting wherever possible.
5. 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.\textsuperscript{5}

5.1 Surgery

5.1.1 Patients Who May Benefit From Surgery

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

5.1.2 Training and Experience of Surgeon

- Neurosurgeon (FRACS or equivalent) with adequate training and experience that enables institutional credentialing and agreed scope of practice within this area.\textsuperscript{5}

5.1.3 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

In Western Australia the State neurosurgical centre is based at Sir Charles Gairdner Hospital which is able to provide all necessary treatment services

5.2 Radiation oncology

5.2.1 Patients Who May Benefit From Radiation Oncology

- All patients should be considered for radiation oncology either alone or with concomitant chemotherapy.

5.2.2 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 including agreed minimum patient numbers in order to practice.\textsuperscript{5}
5.2.3 Hospital or Treatment Unit Characteristics

Staff

Staffing includes:

- nurses
- radiation oncologist as specified in 2.2
- radiation oncology medical physicist
- radiation therapist.

Facilities

- ability to treat patients within three to four weeks of surgery
- Modern linear accelerator equipment and computer planning facilities capable of utilising high quality CT and MRI planning images. dual modality linear accelerator providing, for example, stereotactic radiosurgery
- 3D CRT planning facilities
- Access to psychosocial support services including a clinical psychologist.

5.3 Medical Oncology

5.3.1 Patients Who May Benefit From Medical Oncology

- A multidisciplinary team should consider all patients for chemotherapy.

5.3.2 Training and Experience of Medical Oncologist

- Medical oncologist (FRACP or equivalent) with adequate training and experience that enables institutional credentialling and agreed scope of practice within this area, including agreed minimum patient numbers in order to practice. (approximately 30 new neuro-oncology patients per year).

5.3.3 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 therapies for selected patients may be given in secondary, regional or primary care settings (where no medical oncologist is locally available) by another medical practitioner or nurse chemotherapy provider with training and experience that enables credentialling and agreed scope of practice. This should be in accordance with a detailed treatment plan arising from a MDT setting, and should be under the supervision of a medical oncologist with frequent medical oncology review.

Facilities

- The facility has a clearly defined path to emergency care and advice after hours (through Health Direct).
- The facility is able to care for neutropenic patients.
- There is access to haematology testing and MRI imaging, preferably with advanced MRI capabilities (e.g., MRI spectroscopy, MRI perfusion scanning).
- 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. 7
- Guidelines and protocols, in the case of extravasation of drugs are available and understood.
- Access to psychosocial support services including a clinical psychologist.

**Patient Transport**

Adequate transport provision for patients should be provided. This is important because the travelling distance to appropriate services may be significant, especially for patients with a disease or treatment related disability. In particular, patients living in outer metropolitan areas may be disadvantaged as they fall outside of both hospital transport systems and PATS. This is especially important as neurological cancer patients are often legally restricted from driving due to their medical condition.
6. Surveillance (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.

Plan for follow-up

- Duties of the Cancer Nurse Coordinator include, follow up post operatively and after discharge, during planning, coordination of follow up after treatment, and accessing allied health support such as social, physiotherapy, occupational therapy and neurology.
- Follow-up by the neurosurgeon should occur within 8 weeks of surgery
- MRI should be performed 3 months after completion of radiation treatment, subsequent MRI at three- to six-month intervals, depending on clinical circumstances and subsequent progress and/or deterioration.
- The patient should be followed up by a nominated specialist after each scan as a minimum, and sometimes more frequently.
- An agreed MDT follow-up plan should be developed for the majority of patients and a lead clinician nominated to be responsible for the follow-up of each case.
- Patients with ongoing seizures or intolerance of anticonvulsants should be reviewed by the neurologist. There is no evidence to support the long term use of anticonvulsants in patients who have never experienced a seizure, and assessment should be on a clinical basis.
- The dose of Dexamethasone (if used) required needs to be regularly assessed during the post-operative period, during radiation treatment and during after care.
- The general practitioner needs to know the general management plan as well as information about every hospital visit, specialist appointments and results of recent tests.

NB A protocol on anti-epileptic drugs is part of the Australian Guidelines for the management of glioma. 4

Persons involved in follow-up care

- Not all disciplines need to be involved in longer term follow-up. A lead clinician (neurosurgeon, medical oncologist or radiation oncologist) needs to be in charge of follow-up, with involvement of other multidisciplinary team members as appropriate. Multiple appointments to different specialists should be avoided.
- The general practitioner has a key role in coordination of follow-up and in managing day-to-day issues and maintaining communication.
- Psychologist, neuro-psychologist or psychiatrist, as well as the rehabilitation team, have important roles in this stage.
- Neuro-psychological assessment by a clinical psychologist may be helpful to determine specific needs related to any deterioration in cognitive functioning due to the disease.
For rural patients, some aspects of care can be provided locally (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.

Patients require timely access to supportive and rehabilitative services, preferably close to home.
7. Survivorship

The transition from active to post treatment care is critical to ongoing care. It is recognised that for the large majority of adults with high grade gliomas, post-treatment care involves palliation of symptoms and most patients have a poor prognosis. Care should be planned and coordinated. Survivors should have knowledge of their increased risk of persistent or recurrent cancer or treatment related morbidities. This encourages them to actively participate in their continuing post treatment care.

Survivorship may be medically led, particularly through primary care, nurse-led or patient-led. Cancer councils across Australia are developing and evaluating approaches that are patient centred. *Patients surviving neurological cancer treatment have special needs and a very high risk of recurrence and death from disease making it more likely that there will be a need for tertiary centre involvement in follow up.*

**Specific supportive care needs to consider for patients with malignant neurological tumours.**

For patients with neuro-oncological cancer supportive care is crucial and should cover the time from initial diagnosis to the end of life, as most patients will die from their disease.

These needs are assessed throughout the treatment trajectory by the general practitioner, neurosurgeon, medical oncologist, radiation oncologist, nurse practitioner, cancer nurse coordinator and neurologist, and referrals made appropriately.

A clinical psychologist and occupational therapist should be available to provide assistance to patients in terms of pain management, relaxation therapy, distraction therapy and other appropriate interventions. The family could be included in the delivery of these therapies so that the patient has access to support at all times.

The supportive care needs of patients with malignant neurological tumours will vary in severity and complexity along the disease trajectory. Identifying and assessing the supportive care needs of these patients 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 to be aware of the particular needs related to malignant neurological tumours detailed below which may require intervention from specific members of the multidisciplinary team.

Centralised supportive care is often needed for neurological cancer patients, preferably in the form of a dedicated single integrated centre with state-of-the-art physical and neuro-cognitive assessment and rehabilitation facilities. It is essential that patients have timely access to appropriate rehabilitation services and that adequate respite is available to carers. For patients who are able to manage without intensive supportive care, it is hoped that they will be able to access the required support closer to home. It is likely that community support services will be facilitated by communication with the integrated cancer centre.

A centralised multi-level allied health referral centre with cross-service referral and integrated Allied Health multidisciplinary team meetings would best serve the allied health needs of neurological cancer patients.

Long stay services are required for cognitively or physically impaired young people.
A central point of referral for outpatient services, such as Hospital in the Home, Hospital at Home, Rehabilitation in the Home and Homelink would facilitate access to these services for neurological cancer patients.

**Physical needs**

- Headaches can be severe and specific management by the medical specialist is sometimes required. Other techniques, such as relaxation therapy, distraction and massage, may have short term effects in relieving pain. 8, 9
- 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 maintain airway and remove dangerous objects from the area. This may help relieve the anxiety of family and carers. Specialist nurse education should be available from an epilepsy service. 8
- Focal deficits may affect the patient’s mobility and ability to attend to 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. 8
- Alteration in cognitive functioning can affect the patient’s ability to remember and maintain concentration. 8, 10, 11 Strategies to help manage cognitive impairment, such as maintaining written notes, diary and so on, may be helpful. Referral to an occupational therapist or memory clinic may be useful.
- Patients taking high dose steroids need to aware of the possibility of weight gain, cushingoid appearance and myopathy related to steroids and the effects of changes need to be monitored and doses reviewed in light of benefits. Patients should have access to diet therapy services from early in the disease course for advice on weight control in the context of steroid use. 12 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. 12 Thromboembolic prophylaxis should be considered during inpatient admission (after surgery).
- Dysphasia may occur and referral to a speech pathologist may be needed. 8
- Physical impairment can affect mobility and other activities of daily living. Rehabilitation, including physiotherapy and occupational therapy, is usually required.
- Patients need access to dedicated allied health staff educated in the needs of neuro-oncology patients.
- Driving safety assessment should be available.

**Psychological needs**

**Distress**

A poor prognosis and concern about future may cause distress for patients and carers. Sensitive discussion about these concerns, and possible referral by the cancer nurse coordinator and nurse practitioner to palliative care services, social worker, psychologist and/or psychiatrist, may be required. 8, 11

**Depression**

The incidence of depression ranges from 5 per cent to 95 per cent in this group and can be a result of increased dependency. 8, 13 Clinicians should regularly screen patients with malignant neurological tumours 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. 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.

Transportation costs should be considered for funding support as many patients with neurological cancers are unable to drive.

**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.

Assessment for return to work should be provided for patients who may be able to return to the workplace but are unable to function at their previous level.
8. Relapse and Retreatment

This step covers treatment for recurrence. The intent is disease control and palliation of symptoms. Clinical evaluation and patient decision making will determine the focus of the treatment.

Investigative tests and appropriate referrals

- Symptoms suggestive of recurrence should be investigated with MRI
- Advanced imaging modalities such as MRI spectroscopy, MRI perfusion scanning, Thallium scanning, or FLT-PET scanning may be useful in the diagnosis of recurrence.

Multidisciplinary team

Management should be discussed by a multidisciplinary team that includes (in alphabetical order):

- general practitioner
- medical oncologist
- neurologist
- neuropathologist
- neuroradiologist
- neurosurgeon
- nurse
- Nurse Practitioner
- palliative care service
- psychologist (clinical)
- radiation oncologist
- rehabilitation team, including physiotherapist, occupational therapist and speech pathologist if required
- social worker.

General practitioner and palliative care service participation is essential though it is recognised that this will be part of the community care delivered to these patients under the direction of the specialist cancer centre multidisciplinary team.

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, radiation therapy and/or systemic therapy and needs to be offered in a timely manner for optimal benefit to the patient.

Guidelines are required for the ongoing surveillance of patients following a diagnosis and treatment of neurological cancer in order to ensure appropriate assessment and management, as well as:

- timely access to ongoing treatments
- access to transport for treatments
- timely access and appropriate input from supportive services
- timely access to rehabilitative services
- timely access to respite services.
Consideration should also be given to alternative ways of managing surveillance, such as telehealth particularly for those patients in rural settings.
9. Palliative 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.

The WA Palliative Care model defines the appropriate approach to symptom management and end of life care.

It is important that patients and their families receive optimal palliative care and early referral for assessment and advice is recommended, especially for adults with primary brain tumours. Involvement of palliative care services at first recurrence or progression of disease is recommended, as prognosis is poor after recurrence even with subsequent treatment.

It is also important to recognise that a major component of palliative care involves symptom relief and this may require surgical intervention, radiation therapy or chemotherapy.

10. **Recommendations:**

1. Australian evidence based guidelines for the management of brain tumours have been developed and should be endorsed as the basis for care in WA.

2. Streamlined early referral and accurate diagnosis of these malignancies, is required if their current poor prognosis is to be improved.

3. All patients with neurological malignancies should have their case discussed at the weekly Multi-Disciplinary Team meeting at Sir Charles Gairdner Hospital.

4. The role of the neurological cancer nurse coordinator should be consolidated and recognised as an integral part of the care team.

5. Consideration should be given to the development of the ‘nurse practitioner’ role in neuro-oncology in order to help deal with the expected increased workload and workforce demand.

6. Comprehensive multimodality care is required for malignant neurological tumours and should be coordinated through the Sir Charles Gairdner Hospital Neuro-Oncology Unit which is the designated neurological cancer centre for WA.

7. Improved information technology is required to collect basic and tumour site specific data which will allow an audit of outcomes, and could facilitate enhanced communication between specialists and with general practitioners.

8. Neurological cancer patients require equitable access to treatment and supportive care and adequate provision must be made for the subsidised transport of rural patients and for the accommodation of these patients and their carers close to the Cancer Centre. Consideration should be given by the Health Department to developing the appropriate ‘hotel’ facilities to allow this to occur.

9. Patients should have timely access to appropriate, ongoing, and locally accessible rehabilitation services and adequate respite care should be available to carers.

10. A centralised supportive care facility should be developed for neurological cancer patients, preferably in the form of a dedicated single integrated centre with state-of-the-art physical and neuro-cognitive assessment and rehabilitation facilities.

11. A centralised multi-level allied health referral centre with cross-service referral and integrated Allied Health multidisciplinary team meetings, should be developed to serve the allied health needs of neurological cancer patients.

12. Long stay services are required for cognitively or physically impaired young people.

13. A central point of referral for outpatient services (eg: Hospital in the Home, Hospital at Home, Rehabilitation in the Home and Homelink) would facilitate access to these services for neurological cancer patients and should be developed.

14. Improved provision of transport assistance is required for neurological cancer patients, many of whom are legally restricted from driving. This specifically needs to focus on patients in the outer metro area, who fall outside of the catchment for SCGH transport.
References

1. Australian Bureau of Statistics 3303.0 Causes of Death, Australia, 2006

The Neuro Oncology Collaborative of the WA Cancer & Palliative Care Network acknowledges the following document, which has informed this Model of Care:

Patient Management Framework
Central Nervous System Tumour Stream: Malignant Glioma
Published by Metropolitan Health and Aged Care Services Division, Victorian Government
Department of Human Services,
Melbourne Victoria Australia
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