Overview of the Primary Brain Tumour module: Martin's story

This module includes a case study recounting the experience of Martin, a 49-year-old male diagnosed with a Primary Brain Tumour. The module contains five sections:

- Reduce risk
- Find the condition early
- Have the best treatment and support during active treatment
- Have the best treatment and support between and after active treatment
- Have the best care at the end of life

It is recommended that you complete the sections and their related activities in order. This is because each section and each activity includes information that will help you complete the sections and activities that follow.

Learning activities
At times, you will have learning activities to complete. Click on the learning activities button and a list of questions will pop up. The questions will relate to the content you've just read or the video you've just watched.

Videos
There is a video component to this case study that is presented in eight parts. You can watch the video clips when prompted throughout this case study or at any time by clicking on the video icon in the right-side menu. Learning activities throughout the case study will discuss the video and ask questions about it.
Aim

To support the care of the person at risk of or affected by a primary brain tumour (PBT) across the cancer journey, the aim of this module is to facilitate the development of competencies that reflect the Specialist Cancer Nurses' (SCN) role in:

- providing a coordinated approach to care planning, implementation and evaluation
- providing supportive care, information, and education
- assessing and managing disease and treatment related care.
Rationale

Individuals with a brain tumour experience a range of concerns associated with the direct neurological effects of the tumour, the impact of treatment on physical, sensory, cognitive and behavioural function, and the psychosocial adjustments required to cope with an uncertain prognosis and changes in life circumstances. Some will experience a progressive decline in function and greatly reduced lifespan. These changes can be very difficult for the individual and their family and carers to understand and manage. Health professionals require a range of clinical and supportive care skills to assist the person throughout their journey.

There are many points along the cancer journey when Specialist Cancer Nurses (SCNs) can improve outcomes for people affected by the diagnosis of a primary brain tumour (PBT). These include:

Section 1: Reduce the risk
- While little is known about risk factors for PBT, the SCN can provide evidence based information to allay anxieties and address misunderstandings.

Section 2: Find the condition early
- Although no routine screening measures are appropriate for PBTs, SCNs can be alert for signs and symptoms of a PBT.

Section 3: Have the best treatment and support during active treatment
- Whilst tumour characteristics and treatment approaches and effects are individual to each person, the SCN contributes to multidisciplinary care planning and delivery. This may include surgery, radiotherapy, antineoplastic agents, and supportive care.
- Education about potential causes, predictors and development of cognitive and behavioural sequelae of PBTs and their management is necessary to prepare individuals and their family/carers.
- The SCN has an important role in identifying and managing the diverse range of cognitive impairments and mood-related disturbances associated with PBT through timely assessment, education and appropriate referral.

Section 4: Have the best treatment and support between and after active treatment
- Cognitive and behavioural impairments in people with PBT may improve following completion of treatment, but may also worsen due to late effects of radiotherapy, antineoplastic agents, supportive medications, metabolic/endocrine disturbance, or tumour recurrence.
- SCNs have an important role in monitoring for changes post treatment, and preventing and minimising the impact of impairments on a person’s life.
Section 5: Have the best care at the end of life

- A multidisciplinary approach to management of cognitive and behavioural impairments is required for deterioration that may be associated with progressive disease. The SCN acts as a resource for the individual, their family member, and other members of the team to identify appropriate goals for care and effective management strategies.
- Family and carers face significant emotional challenges when caring for a person with PBT experiencing cognitive and behavioural sequelae at the end of life. SCNs play an important role in providing ongoing support to family members and significant others and facilitating access to carer support and other relevant services.
Section 1: Reduce the risk

Objectives

On completion of this section, you should be able to:

1. Interpret key epidemiological trends in age-specific incidence, mortality and survival from primary brain tumours.

2. Explain current evidence regarding risk factors associated with the development of primary brain tumours.
Primary brain tumours in Australia

The World Health Organisation (WHO) lists 120 types of primary brain tumours (PBTs)\(^{11}\) (See Section 3 of this module for full details).

Australia-wide, the crude incidence of primary brain and other central nervous system (CNS) cancers increased 0.3% per year from 1982 to 2004. The increase was mainly in those over 65 years of age who were diagnosed with the aid of Computerised Tomography (CT) and Magnetic Resonance Imaging (MRI)\(^{12}\).

Approximately 1400 people are admitted each year to Australian hospitals for treatment of a PBT\(^{13}\). PBTs made up 1.4% of all cancers in both men and women in 2007\(^{13}\). They account for the highest number of average life years lost of all cancers because they tend to affect younger people and have poor survival outcomes\(^{12}\).

Primary brain cancer is most commonly diagnosed in childhood and in adults 45–70 years of age. In children, brain cancers are the most common malignancy after leukaemia\(^{12}\).

The median age at diagnosis of brain cancers in Australia between 1982 and 2007 was\(^{13}\):
- 57 years for males
- 58 years for females.

Up to 75 years, males have a greater risk of developing a PBT (1 in 153) compared to females (1 in 235). While incidence rates are higher in males for primary CNS cancers (1.3:1), females have a greater incidence of meningiomas (around 1.5:1)\(^{14}\).

For the period 1998–2004, brain cancer had one of the lowest 5-year relative survival rates of all cancers at 19%, with pancreatic, unknown primary, and lung cancers being the only cancers with lower 5 year survival rates\(^{14}\).

Five-year relative survival rates did not improve in the reporting period 1986-1992 to 1998-2004\(^{14}\).
- For males, the rate has deteriorated from 20.8% to 18.5%
- For females, the rate has remained stable at 19.9% to 19.4%.

However some recent reports from trials with specific population groups indicate modest improvements associated with new therapies for some tumour types\(^{15}\).

**Research link:**

A recent trial involving people with Glioblastoma Multiformae reported increase in survival at 5 years from 1.9% with radiotherapy alone to 9.8% for those who had concomitant radiotherapy plus temozolomide\(^{15}\). Click [HERE](#) to access the summary.
## Learning activities

<table>
<thead>
<tr>
<th>Learning Activities</th>
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<tbody>
<tr>
<td><strong>Completed</strong></td>
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Risk factors

Known risk factors for developing PBT in adults are\(^2\):
- increased age
- male sex
- rare familial genetic syndromes

The inherited syndromes involved in a small proportion of all PBTs include Neurofibromotosis 1 (NF1) & 2 (NF2), tuberous sclerosis complex (TSC) and Von Hippel Lindau (VHL)\(^2\).

No specific preventive measures can be recommended to lessen the risk of developing a PBT. There has been difficulty in determining the causes of PBTs due to\(^2\):
- the heterogeneity of these tumours and an historical lack of specificity of diagnosis
- small numbers of specific tumour subtypes
- the use of retrospective study designs, particularly case-control studies.

Three meta-analysis of mobile phone use and risk of brain tumours reported no association or a slightly increased risk\(^6\). A more recent meta-analysis of case-control studies reported some evidence of a link between mobile phone use and an increased risk of tumours especially among users of 10 years or more\(^6\).

Learning activities

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</table>
| 1 | Access “Brain Tumor Epidemiology: Consensus From the Brain Tumor Epidemiology Consortium”\(^7\), and summarise the current consensus regarding brain tumours:  
- Risk factors  
- Prognostic factors |
| 2 | Using an evidence based approach, discuss how you would respond to a relative who approached you seeking guidance in relation to their concerns of developing a brain tumour due to use of mobile phones. |
Section 2: Find the condition early

Objectives

On completion of this section, you should be able to:

1. Explain the impact of primary brain tumours on normal central nervous system structures and function.

2. Identify various diagnostic tests for primary brain tumours and principles for preparing a person for these tests.

3. Provide information, education and support to people undergoing investigation of symptoms of primary brain tumours

4. Respond effectively to initial reactions and key concerns of people affected by a primary brain tumour.
Pathophysiology and clinical manifestations

Brain tumours grow by expansion, infiltration or both. They may spread to other parts of the CNS. Metastases outside the brain and spinal cord are rare. Multifocal disease refers to cells found at intracranial sites distant from the main tumour. PBTs can have a significant effect on anatomical structures of the CNS and their associated functions including:

- Cranial nerves
- Meninges
- Ventricular system
- Cerebrovascular circulation.

The presenting symptoms of PBTs are determined by factors including:

- Location within the central nervous system
- Size and associated oedema of the surrounding brain tissue
- Method of expansion
- Rate of tumour growth.

Clinical manifestations may be divided into three major categories which may impact the individual in isolation or concurrently:

- Focal effects associated with the primary location of the tumour
- Generalised effects of increased intracranial pressure (ICP)
- Effects caused by displacement of brain structures.

Learning activities

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| □ 1. Access a recent anatomy and physiology or neuroscience text. Summarise the structure and function of the following components of the nervous system: |           | - Each of the cerebral lobes  
- Brain stem  
- Hypothalamus  
- Cerebellum  
- Meninges  
- 12 cranial nerves  
- Ventricular system  
- Cerebral blood flow |
2. Describe the potential clinical manifestations associated with tumours affecting the following intracranial locations:
   - Frontal lobe
   - Parietal lobes
   - Temporal lobes
   - Occipital lobes
   - Thalamus
   - Hypothalamus
   - Brain stem
   - Cerebellum

3. Describe the pathophysiology that may be involved in raised ICP in a person with a PBT.

4. Discuss the signs and symptoms which may indicate raised ICP and the nursing and medical responses to prevent and manage raised ICP.

Scene one

Martin presents to the Emergency Department after experiencing a focal seizure and left sided weakness.

Learning activities

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<th>Learning Activities</th>
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<tr>
<td>1. Identify the symptoms experienced by Martin and discuss their possible pathological basis.</td>
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<tr>
<td>2. Martin’s symptoms had been present for a number of months and he had visited his GP a couple times. How could these factors impact on Martin and Lynn’s experience at this time?</td>
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<tr>
<td>3. Discuss the immediate nursing assessment required when Martin presents to the hospital emergency room.</td>
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<td>4. Outline strategies that a specialist neuro-oncology nurse could use to enable nursing colleagues in emergency rooms and radiology departments to support a person such as Martin suspected of a neurological malignancy.</td>
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</table>
Responding to a new symptom

Screening tests are unavailable or inappropriate for PBTs as early detection does not increase the benefit of treatment. An exception is the potential use of genetic testing to identify individuals with neurofibromatosis type 1. These individuals are at risk of developing optic glioma, a slow-growing tumour which can impair vision\(^{12}\).

Health professionals must be vigilant to investigate suspicious signs and symptoms. Symptoms are often non-specific and may be subtle. The following signs and symptoms should be investigated promptly\(^{18,19}\):

- 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.

Individuals presenting to their GP with these symptoms should undergo:\(^{19}\):

- History and neurological examination
- Brain CT scan, with and without contrast, within 24 hours of request

Further evaluation including funduscopy and a focused neurological examination would involve assessment of\(^{20}\):

- Mental status
- Cranial nerves
- Motor, sensory and cerebellar functions
- Deep tendon reflexes.

Urgent referral to a neurosurgeon is required where the scan shows a lesion. The person should be informed that preliminary investigations indicate some abnormalities that require further investigation. They should not drive until neurosurgical review\(^{18,19}\).

Learning activities

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<tr>
<td>□</td>
<td>1. Discuss the challenges of accessing specialist opinion and referral to tertiary centres for a person living in a rural or remote area who is suspected of a PBT.</td>
</tr>
<tr>
<td>□</td>
<td>2. Describe potential strategies for overcoming these challenges.</td>
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<tr>
<td>aspects of brain tumours.</td>
<td></td>
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<tr>
<td>- Identify the circumstances in which it may be relevant to refer an individual to a Cancer Genetics Service or Familial Cancer Clinic.</td>
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</table>
Principles of primary brain tumour imaging

CT and MRI form the mainstay of tumour imaging\(^1\). The main aims of imaging of PBTs are to\(^1\):

- Diagnose or refine a suspected diagnosis
- Optimally localise the lesion
- Characterise the lesion
- Assess the lesion’s secondary effects and complications
- Plan surgical and radiation treatment including the provision of input data for neuronavigation (image guided surgery)
- Quantify therapeutic response
- Recognise post-treatment progression and complications.

CT (with or without the use of intravenous contrast) is most often the first examination to reveal the possibility of an intracranial neoplasm. CT also helps also with the assessment of calcified and haemorrhagic lesions as well as those that may involve bone\(^1,2\).

Contrast-enhanced MRI is the imaging modality of choice for the diagnostic workup of an intracranial lesion because of its superior soft tissue resolution and multi-planar imaging capabilities. MRI has a greater accuracy in lesion depiction compared with CT\(^1,2\).

Other imaging modalities used within the management of PBTs include\(^\)\(^2\):

- Magnetic resonance angiography
- Functional magnetic resonance imaging
- Magnetic resonance spectroscopy
- Positron emission tomography

Resource link

Click HERE and access Table 5 outlining the uses of imaging modalities in the management of PBTs\(^2\)

Learning activities

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<tr>
<td>□</td>
<td>1. Distinguish between MRI and CT scanning in the diagnostic phase for PBT in terms of (a) rationale for use; (b) potential risks.</td>
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<tr>
<td>□</td>
<td>2. Describe how you would explain an MRI to a person undergoing investigations for suspected brain tumour</td>
</tr>
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<td>□</td>
<td>3. Outline the clinical and supportive nursing interventions for an individual before and after the following:</td>
</tr>
<tr>
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<td>• Brain MRI with contrast</td>
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</table>
Case study link

Click HERE to view Martins CT scan report – 1 December.

* Final Report *
CT SCAN OF BRAIN + CONTRAST
DEPARTMENT OF RADIOLOGY
***** HOSPITAL

CT BRAIN
(With contrast)
Clinical History: Headache, focal seizure left arm.
Technique: Pre and post contrast exam performed.

FINDINGS
There is an ill-defined heterogeneously enhancing mass lesion right temporoparietoccipital lobe. There is peripheral enhancement with central hypodensity consistent with necrosis. There is mass effect on the adjacent sulci as well as the right lateral ventricle. There is midline shift to the left with subfalcine herniation. The findings are most likely due to a primary neoplasm such as glioma. There is no posterior fossa abnormality. There is no hydrocephalus. The skull base and calvarium are normal.

Dr **************
AMY : 01/12/XX
Reported by: **************
Requested by: **************
Location: ED **************
Accession Nbr:
Request Date: 30/11/XX
Exam Date : 30/11/XX
Pre-operative MRI
* Final Report *
Magnetic Resonance Imaging Brain
Magnetic Resonance Imaging Brain performed on 2-DEC-XX, 03:43 PM

REPORTED CREATED BY: ***************
REPORTED APPROVED BY: ***************

REPORT TEXT:
Clinical details:
? High grade glioma
Technique:
Multiplanar, multi sequence imaging, including postcontrast imaging has been performed.

FINDINGS:
There is a large heterogeneous, enhancing mass involving the right frontotemporoparietal lobes. The mass is predominantly solid but has several cystic cavities within. There is surrounding vasogenic oedema. Measurements are as follows: 8.4 cm AP; 4.9 cm CC; 4.6 cm ML. The mass involves grey and white matter.
There is mass effect, with attenuation of the surface sulci. There is compression of the midbrain and there is midline shift to the left of approximately 1.3 cm.
Entrapment hydrocephalus of the left lateral ventricle is secondary to subfalcine herniation. In the right posterior temporal region there appears to be some thickening of the overlying dura.
No other intracranial lesion is seen.

CONCLUSION:
The above findings are consistent with a cerebral neoplasm such as a GBM.
## Learning activities

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</table>
|           | 1. Review the radiology reports from Martin's preoperative CT and MRI, and:  
- Discuss implications of the findings in terms of the clinical signs and symptoms that Martin may experience. |
Experience of diagnosis

A neurosurgeon manages care of the person with a likely diagnosis of PBT in a ward or intensive care setting, depending on the severity of their symptoms.

Surgery is undertaken to determine tissue diagnosis (biopsy) and resection of the tumour if it is accessible. Definitive diagnosis can only be achieved with histological examination of representative tissue from the lesion. The ability to accurately determine the tumour type is based on several factors including:

- The characteristics of the tumour
- The variability within the sample
- The expertise of the neuro-pathologist.

Inter-observer variation in the diagnosis and grading of gliomas has been reported. An expert neuro-pathologist should be consulted to reduce diagnostic error.

Key recommendations from the Clinical practice guidelines for the management of adult gliomas: astrocytomas and oligodendrogliomas provide principles for diagnosis:

- A tissue diagnosis should be obtained in all individuals with a suspected high-grade astrocytoma before commencing definitive treatment
- Antineoplastic treatment should not be offered without a tissue diagnosis unless biopsy is considered too dangerous.

A number of factors contribute to the extreme distress experienced by individuals and their families at presentation:

- The possibility of diagnosis with a life threatening tumour
- Morbidity related to disease and treatment related effects
- The suddenness of surgical intervention
- The use of medical terms such as “lesion”, “tumour”, and “cancer”
- Waiting for a week or longer following surgery for an accurate diagnosis through tissue pathology and possible specialist neuropathology review.

The individual and their family have numerous informational and supportive care needs during this period. Specific requirements for the person undergoing neurosurgery include preoperative baseline neurological examination, and preoperative teaching specific to the planned surgical procedure, including:

- Preparatory measures
- Postoperative routines
- Measures to prevent complications
- Medications to be administered.

For a review of general preoperative supportive interventions, refer to the EdCaN Supporting Module “Fundamentals of cancer surgery”.

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**Learning activities**

**Learning Activities**

<table>
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</table>
|           | 1. For the person who is to undergo surgery for suspected PBT, describe in detail nursing interventions to:  
  - Allay anxiety  
  - Provide information. |
|           | **Scene two** |

**Martin and Lynn express their concerns the night before Martin's surgery.**

**Learning activities**

**Learning Activities**

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<tr>
<td></td>
<td>1. Outline the potential fears and sources of distress for the Reid family in this preoperative period, and how you would assess for these.</td>
</tr>
</tbody>
</table>
|           | 2. Appraise the response by the nurse related to the Reid’s concerns about their children.  
  - How do you respond in such situations?  
  - What resources and supports are available for families at this time in your facility? |
|           | 3. Discuss how you would respond to Lynn’s statement “this is just too much too soon” |
|           | 4. Discuss methods to improve retention and comprehension of information provided to Martin and Lynn at this time |
Section 3: Have the best treatment and support during active treatment

Objectives

On completion of this section, you should be able to:

1. Discuss the implications of histopathology results of primary brain tumours for a person’s cancer journey.

2. Discuss the key supportive care needs of people diagnosed with and undergoing treatment for primary brain tumours.

3. Discuss current treatment approaches for the management of different grades, histologic types and sites of primary brain tumours.

4. Use evidence-based approaches to facilitate the ability of the person affected by primary brain tumours to participate in decisions about their treatment and care, according to their preferences.

5. Apply evidence based pre- and post-operative nursing care for people undergoing surgery for primary brain tumour.

6. Identify the possible effects associated with modalities used in the treatment of primary brain tumours.

7. Implement evidence based interventions to respond to disease and treatment related effects associated with primary brain tumours.

8. Implement supportive care interventions, including referral, to meet the multiple needs of people affected by a brain tumour.
Types and grading of primary brain tumours

CNS tumours are classified according to primary location and cells affected. The nervous system contains neurons and glial cells. In the CNS, glial cells are subdivided into four main types:

- Astrocytes
- Oligodendrocytes
- Ependymal cells
- Microglia.

Glial cells are the major source of primary tumours in the CNS.

The World Health Organisation (WHO) lists 120 types of primary brain tumours (PBTs). CNS tumours are classified into the following groups:

- Tumours of neuroepithelial tissue
- Germ cell tumours
- Tumours of cranial and paraspinal nerves
- Tumours of the meninges
- Lymphomas and haematopoietic neoplasms
- Tumours of the sellar region
- Metastatic tumours.

The major types of primary tumours, comprising 60% of all PBTs, include astrocytomas and oligodendrogliomas, ependymoma, meningioma, (usually benign) and pituitary adenoma (benign).

Click HERE to access Table 1: Distribution of astrocytomas and oligodendrogliomas

Table 1
Distribution of astrocytomas and oligodendrogliomas

<table>
<thead>
<tr>
<th>Tumour type</th>
<th>Percentage of all gliomas (%)</th>
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</thead>
<tbody>
<tr>
<td>Astrocytoma grade I (pilocytic)</td>
<td>4</td>
</tr>
<tr>
<td>Astrocytoma grade II (diffuse)</td>
<td>10</td>
</tr>
<tr>
<td>Astrocytoma grade III (anaplastic)</td>
<td>22</td>
</tr>
<tr>
<td>Glioblastoma multiforme (grade IV)</td>
<td>52</td>
</tr>
<tr>
<td>Oligodendroglioma grade II</td>
<td>3</td>
</tr>
<tr>
<td>Oligodendroglioma grade III (anaplastic)</td>
<td>4</td>
</tr>
<tr>
<td>Mixed oligoastrocytoma grade II &amp; II</td>
<td>1</td>
</tr>
<tr>
<td>Not able to be graded</td>
<td>4</td>
</tr>
</tbody>
</table>

Tumour grading is key to predicting behaviour of a tumour and determines management approaches. The WHO classification system for CNS tumours includes a grading scheme which applies to the range of CNS tumours. Defining characteristics include:

- Grade I
  - Lesions with low proliferative potential
  - Possibility of cure following surgical resection alone
• Grade II
  o Tumours infiltrative in nature
  o Despite low-level proliferative activity, often recur
  o Some tend to progress to higher grades of malignancy

• Grade III
  o Lesions with histological evidence of malignancy

• Grade IV
  o Cytologically malignant, mitotically active, necrosis-prone neoplasims
  o Associated with rapid pre- and postoperative disease evolution and fatal outcome
  o May have widespread infiltration of surrounding tissue
  o May have propensity for craniospinal dissemination
Click [HERE](#) to access Table 2: Summary of epidemiological and pathological features of the common glial tumours*


Table 2: Summary of epidemiological and pathological features of the common glial tumours*

<table>
<thead>
<tr>
<th></th>
<th>High-grade glioma</th>
<th>Low-grade glioma</th>
</tr>
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<tbody>
<tr>
<td><strong>Astrocytic tumours</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>WHO designation</td>
<td>Glioblastoma</td>
<td>Anaplastic astrocytoma</td>
</tr>
<tr>
<td>Synonyms</td>
<td>Glioblastoma multiforme</td>
<td>Malignant astrocytoma, high-grade astrocytoma</td>
</tr>
<tr>
<td>WHO grade*</td>
<td>IV</td>
<td>III</td>
</tr>
<tr>
<td>% of astrocytic tumours</td>
<td>60-75%</td>
<td>10-15%</td>
</tr>
<tr>
<td>Incidence</td>
<td>3-4/100,000/year</td>
<td>0.25/100,000/year</td>
</tr>
<tr>
<td>Peak age of presentation</td>
<td>45-75 years, mean 61 years</td>
<td>45-50 years</td>
</tr>
<tr>
<td>Macroscopic appearance</td>
<td>Cystic, necrotic, haemorrhagic</td>
<td>Infiltration without tissue destruction</td>
</tr>
<tr>
<td>Microscopic appearance</td>
<td>Highly malignant with microvascular proliferation and/or necrosis</td>
<td>Increased cellularity, nuclear atypia and mitoses</td>
</tr>
<tr>
<td>Median survival</td>
<td>12-15 months</td>
<td>2-3 years</td>
</tr>
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<table>
<thead>
<tr>
<th><strong>Oligodendrogial tumours</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>WHO designation</td>
</tr>
<tr>
<td>WHO grade*</td>
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<tr>
<td>% of glial tumours</td>
</tr>
<tr>
<td>Incidence</td>
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<tr>
<td>Peak age of presentation</td>
</tr>
<tr>
<td>Macroscopic appearance</td>
</tr>
<tr>
<td>Microscopic appearance</td>
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<tr>
<td>Median survival</td>
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Learning activities

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<tr>
<td></td>
<td>1. Define the following terms and explain their clinical relevance in PBTs.</td>
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<td></td>
<td>• Benign</td>
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<tr>
<td></td>
<td>• Malignant</td>
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<td></td>
<td>• Diffuse</td>
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<tr>
<td></td>
<td>• Pilocytic</td>
</tr>
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<td></td>
<td>• Anaplastic</td>
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<tr>
<td></td>
<td>• Primary</td>
</tr>
<tr>
<td></td>
<td>• Secondary</td>
</tr>
<tr>
<td></td>
<td>2. Access The 2007 WHO Classification of Tumours of the Central Nervous System, and review table 2. Discuss the implications of a person's tumour classification and grading for the SCN's care planning process.</td>
</tr>
</tbody>
</table>
High-grade astrocytomas

High-grade astrocytomas are the most common type of PBT. They occur most frequently in the sixth to eighth decade of life and are slightly more common in males than females.\textsuperscript{12}

High-grade astrocytomas include WHO grade III (anaplastic astrocytoma, AA) and grade IV (glioblastoma multiforme – GBM) tumours. Increased understanding of the molecular biology of these cancers has enabled further complex descriptions and identification of distinct subtypes. Distinct molecular subtypes of GBM have been identified as primary and secondary GBM.\textsuperscript{12}

High grade gliomas have a very poor prognosis. Overall survival at two and five years is 36% and 28% respectively.\textsuperscript{12} The prognosis of low-grade tumours can be difficult to predict because of difficulties identifying when such tumours will transform to higher grade tumours.\textsuperscript{12}

Tumour grade is the single most important prognostic feature. Other favourable prognostic factors include:\textsuperscript{12,20}

- Age younger than 60
- Good preoperative performance status (Karnofsky performance score greater than 70)
- Absence of tumour necrosis
- Low-grade tumour
- Total or near-total resection
- Frontal lobe compared with temporal or parietal lobe tumours
- Presence of MGMT gene promoter hypermethylation.

The management of high-grade gliomas may involve surgery for biopsy or debulking, radiotherapy, antineoplastic agents or a combination of treatments.\textsuperscript{12}

Learning activities

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</table>
Treatment decision making

Treatment approaches for PBT include:
- Surgery – biopsy vs debulking vs total resection vs wait and see
- Radiotherapy
- Antineoplastic agents.

All individuals with a PBT should be considered for surgery by a neurosurgeon. The person may also be considered for a clinical trial involving the above treatment modalities. A multidisciplinary team (MDT) meeting to plan appropriate care is recommended following histopathological diagnosis. The tumour type, diagnosis and recommended treatment plan should then be discussed with the individual and family members by the most appropriate member/s of the treating team. Discussion should involve:
- Rationale and aim of treatment
- Likely effects
- Possible outcomes
- Other options
- Psychosocial supports available for the individual and family.

The individual and their family should be made aware of their options to seek second opinions at any time throughout their treatment trajectory:
- Clarify questions
- Decide which doctor they prefer to manage their condition
- Decide on treatment options
- Reinforce the accuracy of advice already obtained
- Enhance the person’s confidence.

In some circumstances treatment may not offer a benefit in survival or quality of life. Clinical factors impacting upon treatment decision making may include:
- Individual’s age
- Individual’s performance status (PS)
- Feasibility of decreasing the mass effect with surgery
- Resectability, including the number of lesions, location of lesions, time since last surgery (recurrent patients)
- New versus recurrent tumour
- Suspected pathology – benign versus malignant, possibility of other non-cancer diagnoses, projected natural history.

Cognitive deficits are common with PBTs and can impair the persons’ abilities to comprehend information and their capacity to provide informed consent for treatment. Guiding principles for shared decision making include respecting autonomy and acting in person’s best interests.

Most people affected by a PBT want to receive prognostic information because it helps in their decision making. The Clinical practice guidelines for the management of adult gliomas: astrocytomas and oligodendrogliomas identify key points to consider when discussing prognosis:
- Timing
- Tailoring to the individual
- Language
- Maintaining hope
- Emotional support.

**Learning activities**

<table>
<thead>
<tr>
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<th>Activities</th>
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<tbody>
<tr>
<td></td>
<td>1. Access the <a href="#">Clinical practice guidelines for the management of adult gliomas: astrocytomas and oligodendrogliomas</a>(^{12}). Discuss strategies the SCN can use to promote shared decision making throughout the treatment trajectory.</td>
</tr>
<tr>
<td></td>
<td>2. Outline nursing responses for a person who wishes to obtain a second opinion regarding their treatment options.</td>
</tr>
<tr>
<td></td>
<td>3. Reflect on your experience with working with individuals who have received a diagnosis of a poor prognosis. Using the recommendations outlined in the <a href="#">Clinical practice guidelines for the management of adult gliomas: astrocytomas and oligodendrogliomas</a>(^{12}), identify specific strategies that may improve communication of poor prognosis.</td>
</tr>
<tr>
<td></td>
<td>4. Access <a href="#">Clinical Considerations for Older Patients With Glioblastoma</a>(^{24}). Summarise additional considerations when planning treatment and supportive care strategies for the older person with GBM.</td>
</tr>
</tbody>
</table>
Multidisciplinary care

Individuals affected by PBTs are seen by health professionals from multiple specialties and disciplines. The use of a MDT to manage the care of this population is supported by national and international guidelines and expert opinion. How these teams are configured and managed has not been widely studied.

Generally, the involvement of the MDT occurs after tissue diagnosis. Involvement of the MDT may occur before surgery for certain tumour subgroups such as brainstem glioma, lesions in eloquent areas, multiple tumours and unusual tumours.

The individual and their family/carers need to understand the role of each team member. One practitioner should be identified early on as the main point of contact for follow up, and point of referral to the appropriate specialist. Recommendations on appropriate membership of the MDT are outlined in clinical guidelines and include medical, pathology and nursing participation, and access to allied health and psycho-oncology services. Australian clinical guidelines highlight the desirability of a brain tumour nurse care coordinator in most settings.

Documentation and dissemination of discussions and outcomes of a MDT meeting are important for other health care providers, contribute to certainty within the treating team and are a medic-legal requirement.

Learning activities

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<th>Learning Activities</th>
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<tbody>
<tr>
<td></td>
<td></td>
<td>1. Outline the key elements of effective MDT functioning in the context of PBT.</td>
</tr>
</tbody>
</table>
The role of the neuro-oncology nurse

Specialist nurses have a key role in supporting individuals and promoting quality of life after a diagnosis of a PBT through\textsuperscript{26-28}:

- Assessment
- Clinical care / symptom management
- Information provision to colleagues, individuals and carers
- Counselling
- Teaching effective coping skills to reduce anxiety
- Referral to other health care professionals
- Coordination of effective continuity of care
- Participation in clinical trials / research
- Acting as a change agent.

Various models of a specialist nursing role in neuro-oncology have been described including the primary or team nursing roles in specialist neurosurgical units and brain tumour care coordinators\textsuperscript{27, 29-30}. More recently, neurosurgical nurse practitioners with expanded scope of practice have been appointed in Australia.

Resource link

A nursing professional development pathway has been developed through Cancer Learning. This resource can be used by nurses entering the specialty of cancer control to guide their professional development opportunities as they advance their practice. Click HERE to access the PLAN resource for nurses caring for individuals affected by CNS tumours in the field of neuro-oncology. This resource is adapted from existing work on the Cancer Learning website.

Learning activities

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</table>
Surgical approaches

For further information on cancer surgery, you may wish to access the EdCaN Supporting module: Fundamentals of cancer surgery.

Surgery is the primary treatment for PBTs. The role of surgery is to:

- Obtain a tissue diagnosis
- Treat symptoms
- Reduce the tumoural mass.

Surgical options include stereotactic biopsy, open biopsy or debulking procedure, subtotal resection, or gross total tumour resection. Advances in technology have enabled safer resection of increased amounts of tumour and shorter hospital stays due to:

- MRI guided neuro-navigation (stereotaxy)
- Functional MRI
- Fibre tracking
- Intraoperative monitoring.

Surgical management is guided by key recommendations from the Clinical practice guidelines for the management of adult gliomas: astrocytomas and oligodendrogliomas.

An awake craniotomy procedure has been reported to have advantages over the standard craniotomy procedure in eligible individuals:

- Faster recovery
- Shortened length of hospital stay
- Decline in post-operative complications
- Higher satisfaction rate.

The procedure takes longer to perform and is associated with higher incidence of seizures, nausea or vomiting and emotional distress. Individuals with acute increases in ICP, sleep apnoea, obesity, emotional instability, decreased level of consciousness or a difficult airway have been identified as ineligible for awake craniotomy.

Learning activities

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<th>Learning Activities</th>
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<tbody>
<tr>
<td>Completed</td>
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<tr>
<td>□</td>
<td>1. Access the Clinical practice guidelines for the management of adult gliomas: astrocytomas and oligodendrogliomas. Summarise the key points and recommendations relating to the surgical management of high-grade astrocytomas.</td>
</tr>
</tbody>
</table>
Pre operative preparation

Baseline assessment
Assessment is undertaken to determine any pre-existing deficits and comorbidities prior to surgery. This includes full neurological examination with mental status examination and cranial nerve, motor, sensory, and cerebellar examinations and cognitive/behavioural assessment.

Psychosocial support
The individual and their family may have fears and anxieties related to their possible diagnosis and the outcomes of surgery.

Consent
Nurses can assist in ensuring the individual is able to provide informed consent through clarifying and reinforcing information provided by the neurosurgeon.

Preoperative clinical requirements
Nurses are involved in the administration and management of preoperative orders to prevent and manage issues associated with PBTs and brain surgery. These can be institution specific and include guidance on:
- Isotonic intravenous fluids
- Blood pressure control
- Corticosteroids
- Anticonvulsants
- Prophylactic antibiotics
- Deep vein thrombosis prophylaxis
- Imaging.

A falls risk assessment is important if the individual has altered mobility and/or cognitive impairment or a history of seizures.

Learning activities

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</table>
3. Discuss local policy and procedures related to safety for the person affected by PBT and the implications for nursing care.
   - Falls risk assessment
   - Seizure risk assessment

4. Access [Neurologic Assessment of the Older Adult; A Guide for Nurses](#), and
   - Summarise special considerations associated with undertaking a neurological assessment of individuals over age 65.
   - Discuss how the SCN can ensure accurate and reliable preoperative assessment of the older adult with a primary brain tumour.
Post operative issues

Surgery and peri operative injuries may cause transient or longer term neurological deficits due to damage of normal surrounding cerebral tissue leading to focal neurological deficits\textsuperscript{34}.

Intraoperative issues include\textsuperscript{32}:
- Neuroanaesthesia
- Hypotension
- Hypothermia
- Hyperventilation
- Venous air embolus.

Initial post operative care occurs in the intensive care, neurosurgical stepdown or high dependency unit ensuring close observation and monitoring for 12 – 24 hours post procedure. Neurological assessment and vital sign monitoring according to individual risks and routine post operative practices is required\textsuperscript{32}.

Most complications requiring surgical intervention occur in the first 6 hours post operatively. A seizure, new onset limb weakness or other neurological change could signal complications requiring further neurosurgical intervention. Cerebral oedema can be masked and/or exacerbated by complications and their management\textsuperscript{32}. Specific neurological complications post operatively include\textsuperscript{32}:
- Haemorrhage
- Increased intracranial pressure
- Peritumoural oedema
- Cerebral infarction
- Pneumocephalus
- Hydrocephalus
- Seizures
- Cerebrospinal fluid leak
- Cranial nerve deficits
- Wound infection.

Individuals undergoing craniotomy can experience moderate to severe pain post operatively\textsuperscript{35}. Challenges to effective pain management include the lack of consensus guidelines and concern about the effects of opioids in this group\textsuperscript{36}.

Postoperative MRI scan, with and without contrast should be obtained 24 to 72 hours after surgery to document the extent of disease after surgical intervention\textsuperscript{12}.

Limited research has been published to support specific craniotomy wound care practices. Institutional procedures will vary from daily application of a dry dressing and no hair washing until clip or suture removal to leaving the wound exposed and allowing hair washing within 48 hours post operatively. A small
A pilot study demonstrated no increase in infection rates when hair was shampooed 72 hours post operatively\(^{37}\).

Many individuals are discharged 2-5 days postoperatively. Individuals require information regarding postoperative effects to monitor for. The neurosurgeon should be contacted urgently if there is evidence of\(^{23}\):
- Focal neurological deficit
- CSF leak
- Wound infection.

Prior to discharge from hospital, all relevant specialist appointments should be in place and both the individual and the general practitioner be informed\(^{18}\). The individual's support systems and potential discharge needs should be assessed early on in treatment\(^{32}\).

**Resource links**

- Guide to the Care of the Patient with Craniotomy Post Brain-Tumor Resection
- Guide to the Care of the Patient with Seizures, 2nd Edition

**Learning activities**

<table>
<thead>
<tr>
<th>Learning Activities</th>
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<tbody>
<tr>
<td>Completed</td>
<td>Access a current text and the <a href="#">Guide to the Care of the Patient with Craniotomy Post-Brain Tumor Resection</a>(^{32}) to complete the following learning activities:</td>
</tr>
<tr>
<td></td>
<td>□ 1. For the following specific neurological complications associated with craniotomy, outline the clinical manifestations and medical and nursing responses to prevent and manage them:</td>
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<tr>
<td></td>
<td>• Haemorrhage</td>
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<tr>
<td></td>
<td>• Increased intracranial pressure</td>
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<td></td>
<td>• Peritumoural oedema</td>
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<td>• Cerebral infarction</td>
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<td>• Pneumocephalus</td>
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<td>• Hydrocephalus</td>
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<td>• Seizures</td>
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<td></td>
<td>• Cerebrospinal fluid leak</td>
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<td></td>
<td>• Cranial nerve deficits</td>
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<td></td>
<td>• Wound infection.</td>
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<td>□ 2. With reference to current evidence, discuss the approaches to prevent, assess, and manage post surgical pain in individuals post craniotomy.</td>
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</tbody>
</table>
3. Outline the wound care practices in your clinical environment. Appraise these practices in light of current evidence.

Case study link
Click HERE to access Martin’s surgical report – 5 December

Day of Surgery MRI with fiducial markers
* Final Report *

Magnetic Resonance Imaging Brain
Magnetic Resonance Imaging Stereotaxis performed on 5-DEC-XX,03:00 PM REPORTED CREATED BY: ******************
REPORT APPROVED BY: ******************
REPORT TEXT:
Post contrast 3D volume acquisition T1 weighted MRI brain performed with fiducial markers in place for stereotaxis.
Large heterogeneously enhancing complex solid/cystic mass in the right temporal and parietal lobe noted, with mass effect causing effacement of the right lateral ventricle and 1.2 cm midline shift to the left. Please refer to recent diagnostic MRI (2 Dec XX).

Operation Report
Patient: **************  MRN: **************
Age: 49 years  Sex: Male  DOB: 02/02/XX
Associated Diagnoses: None
Author: ******************
Attachments: None

Operative Note

Date of Operation: 5/12/XXXX.

Surgeons
Surgeon In charge: ******************.
Operating Surgeon: ******************.
Assisting Surgeon/s: ******************.

Operation Status
Unplanned return to operating theatre: No.
Operation Type: Elective.
Wound classification: Clean.

Operating Theatre
***************: OR 8.

Indicators/Background
Large right temporal and parietal brain tumour

Primary Operation Performed
Stereotactic right temporal craniotomy and microsurgical debulking
Item Numbers: 39709, 40803.

Operation description
- under GA, supine, head in Mayfield, turned to left, registration of stereotaxy, minimal shave, Mannitol, IV antibiotics, prep and drape.
- right temporal skin incision, retraction of myocutaneous flap.
- right temporal and parietal craniotomy, dura opening.
- stepwise debulking of tumour through a temporal lobectomy with preservation of posterior superior temporal gyrus, which seems not be infiltrated by tumour.
- lateral ventricle opened, amygdala and hippocampus preserved. Parahippocampal gyrus resected, tentorial incisura with Cranial Nerves II-IV and carotid artery identified.
- subpial debulking towards sylvian fissure anteriorly.
- throughout the case significant bleeding from the highly vascular tumour.
- frozen section: high grade glioma.
- in the end, remnants of tumour are left close to entry point of Labbe vein into sigmoid sinus due to bleeding tendency in this area and towards tentorial incisura/ambient cistern to protect underlying structures.
- meticulous hemostasis, duraclosure (duragen), reinsertion of flap (Synthes screws and plates), layered wound closure.
- sterile dressing.

**A specimen was sent to pathology**

**Post Operative Orders**
- neuro-obs q 1 hour
- diet as tolerated when awake
- mobilise as tolerated
- continue Dexamethasone 4mg bd
- Cefazolin 1 g IV tds for 24 hours
- CT brain Day 1 post op.

**NOTE:**
The patient is not a TPU/DO-EDO patient. MO review is required before discharge.
* Final Report *

Brain MRI
performed on 7-DEC-XX, 12:13 PM
REPORT CREATED BY: ******************
REPORT APPROVED BY: ******************
REPORT TEXT:

Clinical history:
Resection of right temporal and parietal lobe tumour in the past 48 hours.

Technique:
MRI of brain with contrast.

Findings:
Comparison is made to the previous study 5 Dec XX.

Since the previous study, there has been an overlying right parieto-temporal craniotomy with creation of a surgical cavity. The previously seen arterially enhancing lesion within the right temporal-parietal region has been excised, and there has been a near complete right temporal craniotomy. There is a small amount of blood, CSF, and air within the surgical bed. A small amount of acute blood layers a mildly dilated left lateral ventricle. There is mild right sided uncal herniation that was seen on the previous examination.
Learning activities

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</table>
Discharge Summary

GP: **********************
**********************
**********************
PHONE: **********************
FAX: **********************

PATIENT NAME:
**********************
MRN: ***** DOB: 02/02/XX
49 Years Male
**********************

HOME PH: **********************
MOBILE: **********************

ADMIT DATE: 01/12/XX DISCHARGE DATE: 10/12/XX
ATTENDING PHYSICIAN: **********************
WARD AT DISCHARGE: **********************

Diagnosis

REASON FOR ADMISSION:
Tumour

PRINCIPAL DIAGNOSIS:
right temporal GBM

ADDITIONAL DIAGNOSES/COMPLICATIONS:
T2DM
hypertension
hypercholesterol

Interventions, Progress and Follow-Up

PROCEDURES/INTERVENTIONS:

<table>
<thead>
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<th>DATE</th>
<th>PERFORMED BY</th>
<th>RESULT</th>
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<tr>
<td>debulking of right temporal and occipital brain tumour</td>
<td>05/12/XX</td>
<td>Prof **********, Dr **********</td>
<td></td>
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</tbody>
</table>

SUMMARY OF PATIENT PROGRESS:
Thank you for seeing 49 yr male presenting with right temporal mass

Patient presented to A&E following 2/12 history of headaches, Left lower limb deficits and focal seizure activity in left arm. Right temporal lesion on CT brain
Patient was admitted under Prof ********** and had debulking of right temporal lobe tumour. Patient was in ICU for 1 day post op for monitoring and discharged to ward day day 1 post op. Patient was reviewed by endocrine
whilst as an inpatient, insulin increased in dose and dexamethasone was weaned off post surgery.

Patient had seizure whilst on the ward day 2 post op and was started on keppra for seizures. Histopathology of patient returned as glioma grade 4. Radiation oncology reviewed patient and will refer patient for radiotherapy as well as referral for chemotherapy.

Patient discharged home advised not to drive or heavy sports

Follow up as planned

PATIENT DESTINATION :
Discharged home

FOLLOW-UP TO BE ARRANGED BY GP:
LMO 5 days for wound review and medication review and chase BSL and keppra level

FOLLOW-UP APPOINTMENTS MADE:
RAD AND MED ONC AS OUTPATIENT, WILL BE CONTACTED
# Allergies and Medication Details

## Allergies:

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<tr>
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<th>REACTION</th>
<th>COMMENTS</th>
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## Medication on Discharge:

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<th>DOSE</th>
<th>FREQ</th>
<th>ROUTE</th>
<th>MEDICATION STATUS</th>
<th>PHARMACY SUPPLY</th>
<th>COMMENTS</th>
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<tr>
<td>avapro</td>
<td>150mg</td>
<td>mane</td>
<td>Oral</td>
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<tr>
<td>ezetrol</td>
<td>10mg</td>
<td>mane</td>
<td>Oral</td>
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<tr>
<td>Lantus</td>
<td>36units</td>
<td>nocte</td>
<td>Subcutaneous</td>
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<tr>
<td>novorapid</td>
<td>16units</td>
<td>TDS</td>
<td>Subcutaneous</td>
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<tr>
<td>somac</td>
<td>40mg</td>
<td>BD</td>
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<td>80mg</td>
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<td>Continue until review in outpatients</td>
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<td>BD</td>
<td>Oral</td>
<td>New Medication</td>
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**Review by Endocrine team re. optimisation of BSLs post weaning of steroids:**

- When on dexamethasone 1mg mane: Lantus 28 u and 10 units TDS
- When dexamethasone weaned off: Lantus 20 units and 6 units TDS
Scene three

Martin prepares to leave hospital following his craniotomy. He reflects upon changes in his life.

Learning activities

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<th>Learning Activities</th>
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<tbody>
<tr>
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<tr>
<td>□ 1.</td>
<td>Outline a discharge plan for Martin post craniotomy, addressing his current and potential information and supportive care needs.</td>
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<tr>
<td>□ 2.</td>
<td>Outline the education you would provide Martin and his wife regarding his medication upon discharge.</td>
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<tr>
<td>□ 3.</td>
<td>Review Martin’s medical history and discuss the implications associated with Martin being prescribed dexamethasone.</td>
</tr>
<tr>
<td>□ 4.</td>
<td>Discuss how you would provide discharge education to Martin and Lynn regarding signs and symptoms of the following post operative complications:</td>
</tr>
<tr>
<td></td>
<td>• Focal neurological deficit</td>
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<td></td>
<td>• CSF leak</td>
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<td></td>
<td>• Wound infection</td>
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<tr>
<td>□ 5.</td>
<td>Discuss the first aid advice you would provide to Martin and Lynn regarding seizures</td>
</tr>
<tr>
<td>□ 6.</td>
<td>Access Brain tumours and driving: a guide for clinicians, and discuss the information and supportive care you can provide individuals affected by suspension of their licence. Describe how you would address Martin’s concerns about not being able to drive.</td>
</tr>
</tbody>
</table>
### CLINICAL DETAILS
Frozen section of right temporal parietal brain tumour.

### FROZEN SECTION REPORT
1. Examined by frozen section and reported by Dr. *************** on 09/12/XX as "high grade glioma".

### MACROSCOPIC DESCRIPTION
1. LABELLED 'RIGHT TEMPORAL BRAIN TUMOUR'.  Block 1A frozen section block, 1B-1D the remainder of the specimen.

2. LABELLED ‘RIGHT TEMPORAL BRAIN TUMOUR’.  Three irregular and partially haemorrhagic grey fragments of tissue ranging in sizes from 10-40mm in maximum dimension.  Block 2A-2D representative sections of the specimen.

(TM/TT 9/12/XX)

### MICROSCOPIC REPORT
1. Type of specimen: Open.
2. Biopsy site: Right temporal lobe.
3. Size of specimen: 40-50mm.
4. TUMOUR:
   - Histological type: Glioma.
   - WHO grade: IV.
   - Mitoses: 4 hpf.
   - Vascular proliferation: Present.
   - Necrosis: Present.

### SUMMARY
Right temporal lobe - Glioma Grade IV (glioblastoma multiforme)

REPORTED BY: ******************* (9/12/XX)
Case study link

Click HERE to access the Neuro-oncology Multidisciplinary Team Report – 13 December

Neuro-oncology Multidisciplinary Team Report

Martin Reid (2/2/XX) reviewed in MDT 13/12/XX.
ECOG 0, 2/12 history of headache

2/12/XX MRI large heterogenous, enhancing mass right frontotemporoparietal lobes, predominantly solid with several cystic cavities, 8.4cm AP, 4.9cm CC, 4.6cm ML, mass effect with midline shift 1.3cm, compression of midbrain.
5/12/XX: Stereotactic right temporal craniotomy and microsurgical debulking/STR : remnants of tumour are left close to entry point of Labbe vein into sigmoid sinus due to bleeding tendency in this area and towards tentoral incisura.


Plan: Review by medical and radiation oncology teams for adjuvant chemoradiotherapy, for discussion re: referral to clinical trials coordinator as possible eligibility for current clinical trial.

Scene four

Martin’s case is discussed in the multidisciplinary team meeting

Learning activities

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<tr>
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<tr>
<td>□</td>
<td>1. Access NCCN Guidelines Distress Management V1.2011 and Screening for distress in patients with brain cancer using the NCCN’s rapid screening measure, and:</td>
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<tr>
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<td>• Discuss how clinical guidelines could be used in the assessment and management of distress experienced by Martin and his family at this time.</td>
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<td>2. Describe in lay terms the roles of each of the members who participated in the MDT for Martin and his wife.</td>
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Clinical trials

As few as 5% of individuals with glioma are reported to have participated in clinical trials in Victoria between 1998 and 2000\(^{38}\). Key issues affecting clinical trial participation for people affected by PBTs include\(^{38-39}\):

- Abrupt and traumatic nature of a potentially life threatening diagnosis
- Clinical trials viewed as an additional burden to an already stressful situation in which there may not be any personal benefits
- Small numbers of people diagnosed in Australia with less common brain tumours necessitating international collaboration
- Obtaining informed consent from individuals who may suffer cognitive impairment, impairment of judgement and receptive dysphasia
- Individuals affected by a physical disability, thus unable to sign a consent form despite intact cognition.

Due to inclusion of participants with cognitive impairment, effective recruitment strategies\(^{38-39}\):

- Include a system that accurately screens, determines eligibility, and obtains consent by proxy
- Maintain the rights of the participant
- Are acceptable to governing institutional review boards.

Recommendations from other fields of research with cognitively impaired participants may contribute to knowledge in neuro-oncology. Strategies to address barriers in recruitment and retention in Alzheimer’s disease and dementia research include\(^{40-41}\):

- Providing feedback about the individual’s evaluations at each data collection time point
- Increasing public awareness of research opportunities
- Sending newsletters to families to help them stay informed on research findings and study updates
- Having increased communication
- Becoming familiar with the community and recruitment sites before beginning recruitment
- Being flexible with recruitment approaches
- Being aware of cultural differences in participants.

In an effort to ensure well designed, adequately powered and validated research and clinical trials in this population group, there has been international collaboration to map the genomics and clinical outcomes of high grade glioma. Molecular patterns, indicating possible subtypes of GBM have been identified; lending hope to more individually targeted therapeutic options\(^{42}\).

Resource link

Large-scale data integration framework provides a comprehensive view on glioblastoma multiforme [http://genomemedicine.com/content/2/9/65](http://genomemedicine.com/content/2/9/65)
The specialist neuro-oncology nurse role in trials may include:\(^{27}\):

- Obtaining informed consent
- Data management
- Performing neurological investigations, mini-mental state examinations and neurocognitive testing.

For further information on clinical trials, you may wish to access the EdCaN learning resource, [Clinical trials in cancer treatment](#).

### Learning activities

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<tr>
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<tbody>
<tr>
<td>Completed</td>
<td>1. Access <a href="#">Clinical trials in cancer treatment</a> learning resource and complete the learning activities. Focus your responses based on the care of individuals affected by PBT.</td>
</tr>
<tr>
<td>□</td>
<td>2. Access the <a href="http://www.agog.org.au/research.html">Australian Genomics and Clinical Outcomes of High Grade Glioma (AGOG)</a> website, and outline the information you would provide to a possible participant and their carer about the program.</td>
</tr>
</tbody>
</table>

### Scene five

**Martin and Lynn have an outpatient’s appointment to discuss treatment options.**

**Martin and Lynn discuss the treatment options together**
Learning activities

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<td><strong>Completed</strong></td>
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</table>
| ☐                   | 1. Reflect upon experiences of individuals considering entering clinical trials in your facility.  
|                     | - How are they similar or different from the experience of Martin and Lynn?  
|                     | - Discuss resources or supportive strategies SCNs can implement to assist individuals in treatment decision making regarding clinical trials. |
| ☐                   | 2. Discuss the shift in roles for Martin and Lynn which are highlighted in this case and the possible impact that may have on their lives. |
Radiotherapy approaches

Fractionated external beam radiotherapy, postoperatively, in individuals with malignant glioma is well established as a standard adjuvant therapy for individuals with high-grade astrocytomas. Radiotherapy has an important role in:

- Low grade gliomas
- Inoperable, partially resected or recurrent benign brain tumours
- Metastatic brain tumours.

Key recommendations from the Clinical practice guidelines for the management of adult gliomas: astrocytomas and oligodendroglialomas include:

- Individuals with high-grade astrocytoma should have radiotherapy because this extends median survival times when compared to no radiotherapy
- Radiotherapy should start as soon as possible after diagnosis of high grade astrocytoma is established
- The standard radiotherapy dose and fractionation schedule for individuals with high-grade astrocytoma is 60Gy in 2Gy fractions
- For adjuvant radiotherapy for high-grade astrocytoma, conventional fractionation (single daily fractions of 2Gy) is recommended.
- Focal dose escalation with Brachytherapy or stereotactic radiosurgery as part of initial radiotherapy for patients with high-grade astrocytoma does not improve outcome
- There is insufficient evidence to recommend short-course radiotherapy
- For individuals with high-grade astrocytoma, post-operative radiotherapy fields should include the tumour bed with a margin rather than the whole brain.

A typical schedule consists of one treatment per day, five days a week over a 6 week period. Some radiation oncologists offer a shorter (hypofractionated) course of radiotherapy. Whilst further research is required to provide high level evidence for this approach, survival outcomes remain equivalent to standard approaches and there may be advantages for individuals with poor life expectancy.

For further information on radiotherapy, you may wish to access the EdCaN Supporting Resource: Fundamentals of radiotherapy for cancer.

Learning activities

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<tbody>
<tr>
<td>Completed</td>
<td>1. Access a current text and Clinical practice guidelines for the management of adult gliomas: astrocytomas and oligodendroglialomas. Discuss the rationale for the change in treatment approach from whole brain radiotherapy (WBRT) to local-field radiotherapy (LFRT).</td>
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<tr>
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<td>2. Outline the education and resources an SCN would provide to individuals before commencing standard external beam radiotherapy for GBM.</td>
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<td>3. Describe the process of stereotactic radiotherapy and outline the indications, benefits, effects and special considerations for delivery.</td>
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<tr>
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<td>4. Describe the process of interstitial brachytherapy and outline the indications, benefits, effects and special considerations for delivery.</td>
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Radiotherapy effects

Effects may be acute, subacute or delayed.\(^\text{11}\)

Acute effects occur during the course of treatment and are temporary.
- Signs of increased ICP and worsening neurological deficits due to cerebral oedema
- Nausea, vomiting, and anorexia
- Alopecia and skin irritation - the skin becomes dry and peels. Moist desquamation occurs, most often, behind the ears. Click [HERE](#) to access the EdCaN learning resource – Radiation skin reactions
- Extreme fatigue is the most common distressing symptom, occurring during and after treatment. Click [HERE](#) to access the EdCaN learning resource – Fatigue.

Subacute effects develop 1-3 months post completion.
- Temporary
- Anorexia, sleepiness, and lethargy
- Increase in neurological deficits

Delayed effects occur 6-24 months after completion of treatment.
- Often irreversible and often progressive due to direct injury to brain tissue and blood vessels
- Leukoencephalopathy
- Radiation necrosis

Cognitive/behavioural deficits attributed to radiotherapy can occur within weeks of commencing radiotherapy to many years post radiotherapy completion.\(^{43-45}\)
- Acute radiation encephalopathy develops within two weeks of commencing radiotherapy. It results in worsening of pre-existing neurological dysfunction and is rapidly resolved with corticosteroid treatment.
- Early delayed radiation encephalopathy can occur 1-6 months post radiotherapy causing impairments consisting of short term memory loss and attentional deficits. An initial decline in cognitive functioning post radiotherapy often resolves within one year post radiotherapy completion.
- Late delayed radiation encephalopathy is irreversible and follows radiotherapy by several months to many years. Cognitive disturbance is a characteristic of diffuse encephalopathy ranging from moderate deficits like attention or short term memory disturbance to severe cognitive deterioration leading to dementia.

Nursing management involves provision of information, neurological assessment and evaluation and management of effects.

Conventional external beam radiotherapy is usually administered on an outpatient basis. Consider transport needs for these individuals.\(^\text{19}\)
## Learning Activities

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<tr>
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</table>
|           | 1. For the following effects, outline the cause, clinical manifestations and nursing and medical approaches to prevent and manage them:  
  - Leukoencephalopathy  
  - Radiation necrosis |
|           | 2. Access the EdCaN learning resource – Radiation skin reactions and complete the learning activities. Focus your responses on care of the individual affected by a PBT. |
|           | 3. Access the EdCaN learning resource – Fatigue, and complete the learning activities. Focus your responses on care of individuals affected by a PBT. |
Martins blog

Monday

It's been almost three months since I had that first scan. This week marks the end of six weeks of radiation therapy. It has become part of the routine of our lives: a 35 minute drive in the late morning, a 10 minute radiation treatment, lunchtime sandwiches in the Hospital cafe, and another 35 minute return trip. I started out bringing the laptop in and tried to do some work but it just got too hard. Couldn't concentrate and just getting too tired. I find writing easier and actually relaxing.

I will miss the other folks I have met and have seen every day in the waiting room. Our standard appointment times seemed to coincide everyday so I have got to know a few of them and they have provided Lynn and I with much needed support and advice. Got us into the local support group, which I wasn't sure about getting in touch with initially.

It has been an emotional rollercoaster as I have discovered more about my diagnosis - GBM. They told us a great deal at the hospital and gave us all these papers and videos and after the initial shock when I started thinking more clearly again, reading this material and asking a multitude of questions of my healthcare team has helped me to understand more about my condition and what to expect. Also getting on the net has helped when I am up to it. Not saying Lynn and I both don't have our bad days. I sometimes think this is harder for her than it is for me.... It was also good for the older kids to read the brochures and watch the DVDs. Joseph is only 12 so we got them all in touch with Canteen and I think that has helped them all.

Wednesday

There have been so many challenges. The challenge with the biggest impact has been my inability to drive and continue working. As a previously self-reliant and active person the suspension of my license and inability to remain in my job was psychologically devastating, it took away my independence and self worth and made me feel like a “cancer patient”, sick and having to rely on others for help.

Lynn has had to take over the role of driving to chauffeur me to my multitude of appointments and the kids to all their activities. This has been hard on her. She has to do so much. I feel like an incredible burden to others that we ask for help, but our friends and family have been fantastic and so supportive towards my recovery. Thank goodness I had income protection – never think you will need it but it has helped. It is still tough with the kids school fees. We have had to cut back on the luxuries.

The amount of treatment sessions and specialist appointments I attend keeps us busy and is a “full-time” job in itself. I soon realised that I needed an appointment diary that I carried around with me at all times as medical staff were double booking me with appointments and it was difficult to remember my schedule. This diary also helped me to keep a record of my treatment. The medical specialists are...
extremely busy and appointments were often rushed leading us to forget what questions we wanted to ask. This would leave us feeling disappointed and lost. Writing down questions to ask as they came to mind was a strategy we find helpful and then taking this list into the consultation was a way we were about to get our questions answered and left us feeling more in control.

Thursday

Another day another page. The fatigue is bad. As the treatment progressed I became more tired day by day and I sometimes feel completely exhausted, you are really drained. I have learned to set aside time throughout the day to rest or sleep, if I am doing something that will take 1 hour I need another hour to recover. I don't plan a busy day out on the day following a treatment day and I have learned which are the best times of the day for me and plan accordingly. The effects of the tumour have left me with a weak arm and leg, and the occasional small focal seizure but discussing these problems with my healthcare team and receiving the appropriate intervention has kept the impact of these side effects to a minimum. This was difficult initially with opening wrappers, envelopes, holding the phone and other simple activities that I used to take for granted but I have developed ways and strategies to cope with this weakness and I have remained independent in this aspect of my life.

Radiation done, chemo to go.... Bring it on and let's put all this behind us.

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<tr>
<td>□ 1. Outline the effects that Martin’s GBM and treatment regimen is having on his physical and mental wellbeing at this time.</td>
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<tr>
<td>□ 2. Discuss strategies the nurse may initiate to address these effects.</td>
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<td>□ 3. Identify support groups and networks available that may be suitable for people such as Martin and his family</td>
</tr>
<tr>
<td>□ 4. Discuss the financial impact the diagnosis and treatment of a PBT may have on Martin and his family.</td>
</tr>
<tr>
<td>□ 5. Outline the SCN responses to address Martin’s financial concerns.</td>
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<tr>
<td>□ 6. Martin refers to the use of an appointment diary. Outline</td>
</tr>
<tr>
<td>processes and practical supports to support him manage continuity of care and ongoing appointments.</td>
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</table>
Antineoplastic agent therapy approaches

Antineoplastic agents have traditionally had limited value in the management of newly diagnosed high-grade gliomas. Historically, attempts to improve the poor prognosis of people affected by GBM have included changes to radiotherapy schedules, doses and techniques and the addition of nitrosourea-based regimes with little success. Temozolomide first demonstrated some small improvements in response rates in the late 1990s.\(^1\)\(^{15}\)

Subsequently, randomised control trials have demonstrated modest survival benefits with the introduction of temozolomide.\(^{21}\) Temozolomide is an alkylating agent. It is the active metabolite of dacarbazine in an oral form. The drug is lipophilic and can pass through the blood brain barrier.\(^{46}\) Its cytotoxicity is mediated mainly through methylation of the O6-position of guanine. In trials, methylation of the MGMT (a DNA repair enzyme) promoter was the strongest predictor for outcome and benefit from temozolomide.\(^{15}\) A Cochrane systematic review concluded that temozolomide is an effective therapy in GBM for prolonging survival and delaying progression as part of primary therapy without impacting on quality of life and with a low incidence of early adverse events.\(^{47}\)

National and international clinical guidelines now include concurrent radiotherapy and antineoplastic agents and adjuvant antineoplastic agents in the standard of care for individuals with newly diagnosed GBM who have good performance status.\(^{12,15,21,23}\) No recommendations have been made for individuals with performance status 3 or 4.\(^{21}\)

Local administration of carmustine using a biodegradable polymer (wafer) placed intraoperatively in the surgical cavity as an initial therapy has some support due to demonstration of statistically significant survival benefit in individuals with recurrent high-grade gliomas. A number of issues have prevented consensus over the value of carmustine wafers in initial therapy:\(^{12,21}\)

- Drug interactions
- Increased toxicity
- Complications
- Eligibility to participate in clinical trials of other adjuvant therapy
- No evidence for the efficacy or safety of concurrent carmustine and temozolomide.

Resource link

Link to EviQ website for protocols and information
- Glioblastoma Temozolomide concurrent with Radiotherapy (Part 1)
- Glioblastoma Adjuvant Temozolomide (Part 2)
- Glioma High Grade Temozolomide

Merck prescribing information for temozolomide
Learning activities

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<tr>
<td>□</td>
<td>1. Explain why antineoplastic agents have not yet had a major role in management of PBT.</td>
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<td>3. Complete the following in relation to temozolomide:</td>
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<tr>
<td></td>
<td>• Indications</td>
</tr>
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<td></td>
<td>• Mechanism of action</td>
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<td>• Adverse affects</td>
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<td>• Administration considerations.</td>
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</table>
Antineoplastic agent effects

Cognitive effects caused by antineoplastic agents are difficult to separate from those caused by radiotherapy as most individuals who receive antineoplastic agents have adjuvant or concurrent radiotherapy. Cerebral effects of antineoplastic agents occur during or immediately post administration\(^2\). Cognitive / behavioural deficits have not been described with temozolomide use. Encephalopathy with cognitive deficits caused by lomustine, procarbazine, and vincristine (PCV) has been reported with high dose treatments\(^48\).

A recent Cochrane systematic review concluded that Temozolomide did not have a statistically significant negative effect on quality of life and only a low incidence of early adverse events. Grade 3/4 haematological toxicity was found in 5 to 14\%\(^47\).

Individuals receiving temozolomide require monitoring in relation to:

- Myelosuppression
- Lymphopenia
- Fatigue
- Nausea.

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Polypharmacy issues

The management of individuals affected by PBT involves numerous pharmaceutical agents.

- Anticonvulsants
- Anticoagulants
- Antineoplastic agents
- Antiemetics
- Aperients
- Glucocorticoid hormones
- Analgesics
- Benzodiazepines / anxiolytics
- Antidepressants
- Diuretics
- Regular medication for comorbidities.

Many of these agents have significant adverse effects. Potential drug interactions may also effect metabolic clearance, therapeutic effect and cause adverse effects. Two key drug groups which are commonly used include anti-epileptic drugs and corticosteroids.

Anti-epileptic drugs (AEDs)
Older anticonvulsant drugs such as phenytoin, carbamazepine, and valproic acid decrease cognitive functioning resulting in cognitive slowing and attentional impairment\(^{49-50}\). Individuals on anticonvulsants may require monitoring of drug levels\(^{11}\) and careful assessment of potential interactions with antineoplastic agents, anticoagulants and reduced efficacy of corticosteroids\(^{51}\).

Corticosteroids
Corticosteroids are indicated in the management of symptomatic cerebral oedema. Corticosteroids also have a role in reducing radiation-induced cerebral oedema and relieving headache and nausea\(^{12}\). Adverse effects of corticosteroids are related to the dose and duration of treatment. The lowest possible doses of corticosteroids should be used and gradually withdrawn when possible. Corticosteroids (dexamethasone) may cause mood disturbances and rarely psychosis. They also can produce a clinically significant suppression of the immune system and consequently an increased vulnerability to opportunistic infections\(^{52}\). Other effects associated with chronic use include\(^{12,52}\):

- Morbid weight gain
- Cushingoid syndrome
- Hyperglycaemia / diabetes
- Myopathy
- Gastrointestinal effects
- Osteoporosis
- Adrenal insufficiency.
Medication errors and adverse effects may arise for individuals in the community if there is difficulty with following instructions or confusion. Written instructions should be given regarding schedules. The individual and their family need to receive information on the:

- Role of medications
- Effects to observe for
- Indications to call health care provider
- Absolute necessity of taking the prescribed dose.

**Learning activities**

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Supportive care needs

Individuals often experience a range of disease- and treatment-related effects that require active management due to the nature, location, and natural history of primary brain tumours.

Physical effects
- Seizures
- Headaches
- Corticosteroids effects
- Gastrointestinal side effects
- Bone effects
- Skin reactions
- Venous thromboembolism
- Fatigue
- Aphasia
- Focal deficits – mobility, ADLs

Psychosocial effects
- Personality changes
- Body image changes
- Cognitive changes
- Anxiety and depression
Physical effects

Seizures

The incidence of seizures prior to diagnosis is 10-40%. Seizures may arise due to the tumour or as a consequence of surgery. Most seizures due to brain tumours are focal (partial) seizures\textsuperscript{12}.

AED therapies are the mainstay of management. Prophylactic anticonvulsants are not recommended. Treatment should be commenced after the first seizure in individuals with gliomas\textsuperscript{12}.

Learning activities

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<tr>
<td>□</td>
<td>1.</td>
<td>Explain the difference between focal seizures and a generalised tonic-clonic seizure.</td>
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<td>□</td>
<td>2.</td>
<td>Describe the nursing and medical management of a grand mal seizure within a clinical environment.</td>
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</tbody>
</table>
| □                   | 3.       | Outline the information you would provide to the individual and their carer regarding epilepsy management in the community:  
- First aid  
- When to call an ambulance  
- Driving  
- Avoidance of seizure precipitants  
- Medication issues. |
Skin reactions

Cutaneous reactions in the person affected by a PBT may be related to\textsuperscript{12}:

- Cutaneous drug reactions
- Cutaneous eruption of temozolomide and lymphocyte recovery
- Radiotherapy skin reactions.

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Headache

Headaches in people affected by PBT are due to the effect of raised intracranial pressure and invasion of central pain pathways. Headache has been reported in half of all individuals with PBTs. The site of pain may not correlate with the anatomy of the tumour. Management involves decreasing oedema and intracranial pressure. Corticosteroids, simple analgesia and opioid analgesics are used as required. Astute nursing assessment is required in individuals with cognitive and behavioural changes or communication difficulties.

Resource link


Learning activities

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<tr>
<td>☐</td>
<td>1. Outline potential aetiologies of headache in a person who has completed treatment for PBT.</td>
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<tr>
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<td>2. For each aetiology, discuss nursing and collaborative management strategies.</td>
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</tbody>
</table>
Venous thromboembolism

The incidence of venous thromboembolism (VTE) in people affected by malignant glioma is in the range of 16-28% in the first year from diagnosis. The pathogenesis of VTE in this population is associated with:

- Direct secretion of procoagulants from the tumour and/or
- Dysregulation of thrombogenic factors.

Further risk factors include major neurosurgery, glioblastoma histology and age greater than 75 years.

Prophylaxis of VTE involves the use of:

- Non-pharmacological approaches – graded elastic stockings, intermittent pneumatic compression and foot-pump devices
- Pharmacological approaches - antithrombotics

VTE may present as a deep venous thrombosis (DVT) or pulmonary embolus (PE). Diagnosis is made with a duplex Doppler ultrasound for a DVT and nuclear scintigraphic ventilation-perfusion (V/Q) scanning of the lung of CT pulmonary angigram is indicated if a PE is suspected. The D-dimer, together with a careful clinical assessment, may be used to exclude a VTE and avoid unnecessary other investigations.

Anticoagulation is the mainstay of treatment for VTE.

Resource links


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<tr>
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<tr>
<td></td>
<td>1. For deep vein thrombosis and pulmonary embolus:</td>
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<tr>
<td></td>
<td>• Outline the signs and symptoms</td>
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<td></td>
<td>• Describe nursing assessment ensure early identification</td>
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<td>• Outline nursing interventions to prevent VTE</td>
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<td>• Discuss the nursing implications of pharmacological approaches used in the prophylaxis and management of VTE.</td>
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Cognitive and behavioural effects of PBT

Cognitive disturbance is a prominent clinical feature in people with PBTs\(^4, 7, 54-55\). Both the individual and carers report that dealing with these changes can prove to be overwhelming and distressing. Such sequelae may be more disabling than physical or speech impairments, adversely affecting community participation and quality of life\(^56\).

Cognitive and behavioural dysfunction in individuals with PBT can be caused by a combination of factors\(^2, 4, 7, 54-55\):

- The tumour
- Treatment effects (surgery, radiotherapy, antineoplastic agents, and/or corticosteroids)
- Tumour related seizures and anticonvulsant therapy
- Psychological distress.

Damage to the frontal regions of the brain and their connections can result in a diverse range of behavioural changes\(^57\). Three clinically observable ‘syndromes’ have been described in relation to the behavioural changes\(^58-59\).

- **Disorders of regulation**: Associated with lesions to the orbital prefrontal circuit, and are typified by behaviours such as social disinhibition, physical and verbal aggression, limited insight and loss of social judgement.
- **Disorders of activation**: Linked to impairment of the anterior cingulate circuit and effects include apathy, adynamia and perseveration.
- **Disorders in executive cognitive function**: Associated with damage to the dorsolateral pre-frontal circuit. These neural structures and circuits are vulnerable to the local effects of frontal region tumours or the remote effects of tumours located in other brain regions. Effects the integrative component that marshals cognitive processes including attention and memory in order to pursue goal-directed behaviour.

Neuro-behavioural rating measures validated on samples including individuals with PBT are most appropriate to evaluate cognitive and behavioural impairments. The reliability of self reporting may be compromised due to impairments in memory and insight. Measures that capture relative (proxy) and clinician ratings of evidence of cognitive/behavioural impairment are also useful. A variety of screening tools and neuropsychological tests may be used by those with specialised training in use of such tools.

- **Emotional and Social Dysfunction Questionnaire (ESDQ)**\(^60\)
  The ESDQ is a measure of emotional and social dysfunction among brain-damaged populations with a self-rating (51 items) and partner version (52 items) grouped into 8 subscales (e.g. for Partner version - Anger, Helplessness, Emotional Dyscontrol, Indifference, Inappropriateness, Fatigue, Maladaptive, and Insight). Respondents rate all items on a 10-cm visual analogue scale with the anchors being “no problem” and “big problems” producing 8 subscale scores.
- **Frontal Systems Behaviour Scale (FrSBe)**\(^61\)
The FrSBe is a 46-item paper-and-pencil behaviour rating scale that measures impairments of the behavioural and cognitive domains of executive functioning using behavioural descriptors that capture data on how people function in everyday life. There are self-rating and partner versions. The FrSBe includes a Total Score, as well as scores on three subscales related to the three frontal systems behavioural syndromes: Apathy (14 items), Disinhibition (15 items), and Executive Dysfunction (17 items). This scale has good reported reliability and validity.

- **Overt Behaviour Scale (OBS)**
  The Overt Behaviour Scale has been designed specifically to measure the prevalence of challenging behaviours among people with acquired brain injury (including brain tumours) in community settings. The OBS complements data collected using the ESDQ, highlighting people with PBT exhibiting significant behavioural disturbance. The OBS is a 34 item scale that measures 9 categories of challenging behaviours including aggression, inappropriate sexual behaviour, perseveration, wandering, inappropriate social behaviour, and adynamia.

- **Depression, Anxiety and Stress Scale (DASS)**
  The DASS is a 42-item self-assessment questionnaire that measures state related levels of depression, anxiety and stress.

**Learning activities**

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<td>☐ Complete the following learning activities in relation to the following tools:</td>
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Executive functioning

Cognitive changes in people affected by PBTs are multifaceted. They most commonly include executive functioning impairment. Executive functioning refers to the higher order neuropsychological processes that:

- Mobilise/integrate various components of cognitive functioning
- Monitor/regulate behavioural impulses, in order to enable humans to undertake complex goal-directed behaviour, as well as respond adaptively to unexpected or novel stimuli.

The cognitive dimensions of executive functioning include abstract reasoning, planning and problem-solving. Impairments to the behavioural dimensions of executive functioning can be observed in:

- Poor self-monitoring
- Increased irritability
- Disinhibited and egocentric behaviour.

Research among other brain-damaged populations has found that impairments of executive functioning often have a negative effect on employment, relationships and self-care.

The most serious effects of impairments in executive functioning are challenging behaviours. Challenging behaviour is behaviour that is disruptive, makes others uncomfortable, goes against the rules of community living, presents a safety risk to the person or others or distresses the individual themselves or their family/friends. These can include:

- Verbal or physical aggression
- Sexually inappropriate behaviour
- Wandering/absconding
- Perseveration
- Socially inappropriate behaviour (including illegal behaviours, non-compliant behaviours)
- Adynamia.

Challenging behaviours have been associated in other brain damaged populations with poor levels of return to work, exclusion from needed services, increased staffing costs for agencies managing such clients, unwanted admissions to inappropriate institutional care, and significant distress for family and staff exposed to such behaviours.

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| • Verbal aggression  
| • Physical aggression  
| • Sexually inappropriate behaviour  
| • Absconding. |
Mood disturbance

People with PBT may experience psychological distress, anxiety and depression. Changes in mood may lead to deficits in attention, vigilance, and motivation that subsequently effect cognitive/behavioural domains\textsuperscript{73}. Depression has been identified as an important predictor of poor quality of life. Reported prevalence of depression in people affected by brain tumours varies. One study reported self-reported rates (35-93\%) to be much higher than clinician diagnosed rates (15-28\%)\textsuperscript{30}.

Factors associated with the development of depression in individuals with brain tumours include\textsuperscript{12}:
- Female gender
- Left hemisphere lesions
- Frontal location of tumour
- Family history of depression
- High levels of physical disability and cognitive dysfunction.

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Section 4: Have the best treatment and support between and after active treatment

Objectives

On completion of this section, you should be able to:

1. Explain the recommended follow up regimen following active treatment for primary brain tumours.

2. Evaluate evidence regarding the benefits of the nurse-led model of follow up care.

3. Explain the longer term supportive care needs of people following completion of primary treatment for primary brain tumours.

4. Collaborate with other care providers to ensure a coordinated, planned and documented approach to meeting supportive care needs for the person following initial treatment for a neuro-oncological tumour

5. Make appropriate and timely referrals for psychological care and support for the person affected by neuro-oncological tumour

6. Analyse factors which may influence a person's adherence to recommended health care interventions following treatment for a primary brain tumour.

7. Identify signs and symptoms associated with primary brain tumour recurrence.

8. Identify the current management options for recurrent brain tumours.
Follow up treatment and care

Key recommendations from the Clinical practice guidelines for the management of adult gliomas: astrocytomas and oligodendrogliomas regarding follow up include\(^\text{12}\):

- The aim of follow-up is to evaluate tumour control, monitor and manage symptoms from tumour and treatment and provide psychological support.
- The optimal frequency of follow-up visits is unknown and should be determined by the individual’s clinical condition.
- Follow-up should be undertaken in a setting where the person has access to members of the multidisciplinary team.

The Cancer Nurse Coordinator has been identified as having a key role in:

- follow up post operatively and after discharge
- during planning, coordination of follow up after treatment
- accessing allied health support such as social work, physiotherapy, occupational therapy and neurology\(^\text{18}\).

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<tr>
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<td>1. Access the follow up plan recommended in the Patient management framework central nervous system tumour stream: malignant glioma.(^\text{19}) Compare this with practices in your organisation.</td>
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<td>2. Describe principles for ensuring optimal follow up care and coordination of follow up care.</td>
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<td>3. Access the NCCN Guidelines Central Nervous System Cancers. Outline the differences in intent between early and longer term MRI scanning within follow-up</td>
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Survivorship issues

Treatment advances have increased survival times for individuals with PBT. As a consequence, more individuals require rehabilitation services. Survivors of PBT can face some unique concerns. This is because they often continue to receive treatment 18 months post diagnosis, and fear of recurrence can persist over time. Long term changes in emotions, cognition, and health behaviours have been observed in survivors of brain tumours. Survivors have self-identified the following effects which decrease their function:

- Neurologic impairment
- Psychiatric symptoms
- Neurocognitive deficits
- Severe fatigue.

Cognitive and vision impairment are common deficits experienced concurrently and can affect quality of life following treatment. The inability to work and participate in everyday and social activities can be troubling.

Late-delayed radiation encephalopathy is irreversible and a serious disorder causing cerebral atrophy and/or radio-necrosis. Symptoms include:

- Progressive mental slowing
- Deficits in memory and attention
- Gait abnormalities
- Urinary incontinence
- Apathy.

Another late reaction is endocrine disturbance caused by hypothalamic-pituitary axis damage. Most individuals have subclinical endocrine dysfunction with certain hormone insufficiencies and/or dysfunction resulting in cognitive effects.

Learning activities

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<tr>
<td>1. Access <a href="#">Very late relapses in glioblastoma long-term survivors</a>. Discuss the impact these issues may have on GBM survivors and their families / carers.</td>
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<tr>
<td>2. Discuss the causes of fatigue in PBT survivors.</td>
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Behavioural Interventions in the community

Referral to a dedicated Neuropsychologist or a Behavioural Consultancy Service may be required in cases where a significant impairment persists after possible causes have been addressed. Behavioural interventions are useful in managing organically-mediated challenging behaviours\textsuperscript{61}, and to address the functional and psychosocial consequences of their condition\textsuperscript{56, 82}.

The Behavioural Consultancy model provides expert consultation and intervention, in the home environment, to assist families and service providers in the management of challenging behaviours among people with acquired brain injury. A range of cognitive, behavioural and environmental strategies are used to reduce the disabling consequences of behavioural and cognitive impairments. These strategies are delivered within the context of the following six steps\textsuperscript{64}:

1. Site visit
2. Crisis management (if needed)
3. Engagement
4. Intervention
5. Education
6. Ongoing review.

Interventions include direct work with the individual, secondary consultation with family members, and tertiary consultation with linked service providers (e.g. home support staff, community nursing, mental health services). Management interventions are drawn from behavioural/learning theory. It can include:

- The establishment of structured cues
- Time out on the spot
- Differential reinforcement of other activities
- Chaining
- The introduction of compensatory memory strategies
- Restructuring the environment to take an antecedent approach to managing behaviours.

The secondary and tertiary networks of the person with PBT assist in the development of realistic and relevant management approaches. The Consultancy provides training to the secondary and tertiary support networks, in the agreed-upon management approach. Median length of interventions are 6 months\textsuperscript{64}.

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<td>Completed</td>
<td>1. Identify the services in your local area that you can refer carers to when managing behaviours related to executive functioning impairment.</td>
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Rehabilitation

The role of rehabilitation in the person affected by PBT depends on the stage of disease. The aim is restoration of function and shorter duration of hospitalisation in early stages\textsuperscript{12, 52}. Rehabilitation is important for maintaining individuals’ independence and quality of life in advanced stages\textsuperscript{52}.

Rehabilitation often remains underused and poorly investigated\textsuperscript{52}. The \textit{Clinical practice guidelines for the management of adult glioma: astrocytomas and oligodendrogliomas}\textsuperscript{12} make key recommendations regarding the role of:

- MDT assessment
- Physiotherapy
- Occupational therapy
- Speech pathology

Research link


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The experience of carers

Families can experience initial chaos followed by a heavy burden of care, characterised by:\n\begin{itemize}
  \item Powerlessness
  \item Helplessness
  \item Isolation
  \item Reduced health and wellbeing
  \item Financial burden
  \item Physically and mentally exhaustion.
\end{itemize}

A systematic literature review of the supportive care needs of the carers of people with brain tumours identified key challenges and enablers to the caring role\textsuperscript{83}:
\begin{itemize}
  \item The work of caring was described as mentally and physically exhausting, demanding and requiring new roles.
  \item Increased responsibility was perceived for their spouses’ illness and survival, for activities of daily living, researching information on the disease and its treatment, and for providing emotional support and management of physical, cognitive and neuropsychiatric symptoms. Difficult behaviour such as personality changes and erratic emotional behaviour has been reported as the most difficult aspects to deal with, because families often lack the skills and knowledge needed to manage it\textsuperscript{84}.
  \item Living with uncertainty due to the unpredictability of the disease.
  \item Cognitive impairment leading to patient and social isolation was described as ‘social death’.
  \item Stress was present but determining factors were not definitive within the literature.
\end{itemize}

Positive aspects to reduce the burden of caring were identified as\textsuperscript{83}:
\begin{itemize}
  \item Information prepared carers for possible future changes and enabled management of the day to day care needs and problems in the home.
  \item Friends and family providing support was regarded as important and useful. Studies have reported the lack of family and friend support as frustrating for carers.
  \item Health professionals provide information and support regarding issues of life expectancy and survival.
  \item A case manager provides a necessary role in dealing with the emerging emotions, facilitating discussions between the individual and carer and could answer medical and practical questions. Continuity of health care providers helps to establish cohesion and provide hope and a sense of security\textsuperscript{85}.
  \item Support groups overall were identified as positive in supporting carers through:
    \begin{itemize}
      \item Facilitating home care
      \item Reducing spousal anxiety and depression
      \item Troubleshooting difficult situations
    \end{itemize}
\end{itemize}
Providing a forum for caregivers to vent their frustrations
- A source of information and hope.

Resource link

A comprehensive suite of resources for people affected by brain tumours are available. The resources include fact sheets on:

- Anger management
- Stress and anxiety
- Attention to concentration
- Communication
- Disorientation/appearing confused
- Being self centred
- High level thinking or executive impairments
- Fatigue
- Impulsivity
- Inappropriate social behaviour / sexual behaviour
- Lability
- Apathy / lack of motivation
- Neglecting personal care
- Memory loss
- Low mood
- Perservation.

Link to Neuro-Oncology Fact Sheets

*Adult gliomas: a guide for patients, their families and carers* provides information on a range of topics including causes of brain cancer, screening, managing symptoms, navigating the health system and practical advice in areas like rehabilitation and driving.

It also outlines psychological and social support, how to participate in clinical trials and palliative care options. The guide was developed by an expert group, led by Michael Barton OAM, Professor of Radiation Oncology at the University of New South Wales.

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<tr>
<td></td>
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<td>1. Access <a href="#">An exploratory study of GP awareness of carer emotional needs in Western Australia</a> (PDF, 219KB) and <a href="#">Carers and end of life Interim Position Statement</a> (PDF, 130KB).</td>
</tr>
</tbody>
</table>
- Identify and discuss the key challenges experienced by carers of people diagnosed with PBT.
- Discuss specific challenges that may be experienced by carers of different age groups.
Scene seven

Martin presents 15 months post surgery. His wife, Lynn is finding it difficult being his full time carer.

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<td>1. Identify the carer support groups in your area that you would refer a carer such as Lyn to at this time.</td>
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<td>2. Access the Cancer Institute NSW Neuro-Oncology Fact Sheets, and:</td>
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<td>• Identify resources which may be helpful for Martin and Lyn at this time.</td>
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<td>• Discuss practical strategies that the team can implement to support Lyn with her concerns.</td>
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<td>3. Outline strategies to ensure continuity of care between Martin’s care providers at this time.</td>
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Cancer recurrence

Cognitive deterioration can be the first indicator of progressive disease after treatment. It can indicate tumour progression before signs of disease recurrence are evident on CT or MRI. Symptoms suggestive of recurrence should be investigated with MRI. Treatment will depend on the location and extent of the recurrence, and on previous management. The intent is disease control and, in some situations, palliation. Treatment may include surgery, radiotherapy and/or drug therapy.

Management of recurrent disease depends on the individuals’ age, performance status, histology, response to initial therapy, time since original diagnosis, and whether the recurrence is local or more diffuse.

- Local recurrence may be managed with repeat resection, with or without a BCNU-impregnated wafer placed locally in the surgical bed. Individuals with recurrent high-grade astrocytoma, particularly younger, asymptomatic individuals may benefit from resection of tumour.
- Systemic chemotherapy (temozolomide or nitrosourea-based regimens) may be considered if the recurrence is unresectable or there are unacceptable risks associated with surgery.
- Systemic chemotherapy is recommended for diffuse or multiple recurrent disease. A response to further chemotherapy is unlikely after 2 consecutive agents have failed to produce a response.

Best supportive care should be strongly considered if the individual has poor performance status.

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Section 5: Have the best care at the end of life

Objectives

On completion of this section, you should be able to:

1. Analyse an SCN’s role in facilitating the transition to palliative care for people affected by primary brain tumours

2. Undertake a comprehensive assessment to guide management of the person with an advanced primary brain tumour.

3. Analyse the supportive care needs of people affected by an advanced and progressing primary brain tumour across all domains of health.

4. Implement evidence-based nursing interventions relevant to the needs and preferences of the person with an advanced primary brain tumour to optimise their functional abilities at end of life.

5. Identify barriers and enablers to the provision of comprehensive home-based palliative care for people with primary brain tumours at end of life.
Transition to palliative care

Involvement of specialist palliative care services may improve outcomes for individuals with progressive disease, including\textsuperscript{12}:

- Increased individual and carer satisfaction
- Increased time spent at home by individuals
- Reduced time in hospital
- Reduced overall cost of care
- Increased likelihood of the individual dying where they wish.

A number of strategies have been identified to support people affected by PBTs transition to a palliative approach to care\textsuperscript{12,52}.

Communication of diagnosis and prognosis may help facilitating coping strategies. Individuals may not wish to be informed about prognosis so communications should be tailored to the coping styles of the individual and carers.

Early referral is facilitated if palliative care health professionals are established members of the MDT. It is recommended that referrals are based on an individual’s need and not on life expectancy.

A mixed management model of end-of-life care should be considered according to individual needs. It involves close and continuing cooperation between oncology and palliative services through parallel delivery of active treatment and comfort measures and death preparation. Clear communication between all health care providers and the people affected by cancer is imperative to ensure continuity of care and to ensure the individual’s wishes are known.

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<td>1. Discuss how to determine when referral to palliative care should be considered for people affected by PBT.</td>
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<td>2. Discuss implications of issues of cognitive impairment and memory loss affecting the individual with a primary brain tumour for communicating sensitive information associated with prognosis.</td>
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<td>3. Discuss strategies the SCN may use to support the</td>
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<td>individual and their carer during these discussions.</td>
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<td>4. Discuss local strategies which are used to facilitate continuity of care and communication between community, residential and acute hospital settings during end of life care.</td>
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</table>
Supportive care needs in the palliative phase

The aims of palliative care are to maintain and improve quality of life, control distressing symptoms and facilitate a dignified death. Individuals with brain tumours experience a wide range of symptoms which they may have experienced early in their treatment trajectory but at end of life may have different mechanisms and required different management strategies. The most common physical symptoms are:

- Fatigue
- Decreased ability to concentrate and remember
- Loss of independence
- Nausea
- Pain.

Individuals with brain tumours experience a wide range of symptoms which they may have experienced early in their treatment trajectory but at end of life may have different mechanisms and required different management strategies. The most common physical symptoms are:

- Fatigue
- Decreased ability to concentrate and remember
- Loss of independence
- Nausea
- Pain.

Other significant areas of supportive care for individuals with brain tumours at end of life relate to:

- Feeding, fluids and dysphagia
- Cognitive dysfunction, depression and acute confusional state
- Bowel and bladder problems
- Pressure areas
- Corticosteroid use.

Abrupt changes in behaviour, personality or mood may be related to delirium, and this needs to be identified and managed promptly to reduce distress.

Management of seizures at the end of life is complicated by the inability to administer AEDs orally. Intractable seizures at end of life may be due to cerebral haemorrhage, metabolic conditions (hypoglycaemia), medications and substance withdrawal.

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Scene eight

Martin has deteriorated and his cognitive and behavioural changes are impacting upon his family

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<tr>
<td>□ 1. Describe the supportive care requirements of Martin and his family reflected in the vignettes.</td>
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<td>□ 2. Identify the immediate supportive care strategies which could be put in place for Martin and Lynn at this time.</td>
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<td>□ 3. Outline further assessment you would undertake with Martin and his family to ascertain other issues.</td>
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<td>□ 4. Discuss evidence based strategies which may help Martins children prepare for and cope with his death.</td>
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Care at the end of life

A number of contributing factors have been identified as significant in supporting optimal care at end of life\textsuperscript{12}.

- Control, autonomy and independence with respect to pain and symptom control
- Place of death
- Who is present at the time of death
- Maintaining privacy
- Access to information and expertise
- Spiritual and emotional support.

Completing unfinished business may enable individuals to prepare for death by signing wills, contacting loved ones, appointing a power of attorney and completion of advance care directives. Appropriate early and ongoing advanced care planning is important to ensure the individual’s wishes are voiced and the factors are considered to contribute to a ‘good death’\textsuperscript{12}.

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<td>1. Reflect upon the death of a person whom you cared for from PBT. Discuss factors which facilitated optimal end of life care, and areas where the experience may have been improved.</td>
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<td>2. Discuss key principles of advance care planning</td>
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<td>3. Outline how advance care planning is facilitated in your facility.</td>
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<td>4. Access the article Factors influencing death at home in terminally ill patients with cancer: systematic review, and:</td>
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<td>- Outline factors which influence an individual's place of death.</td>
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<td></td>
<td>- Discuss strategies the SCN may use to promote an individual's death at home if it is preferred.</td>
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</table>
References


45. Vigilani MC, Sichez N, Poisson M, Delattre JY. A prospective study of cognitive functions following conventional radiotherapy for supratentorial


