

Includes your
TEMODAL
Patient Diary

The Way AHEAD

A guide for those diagnosed with a brain tumour

This educational booklet is only for use by patients prescribed TEMODAL (temozolomide).
The information in this booklet does not replace information provided to you by your doctor or nurse.
If you have any questions about TEMODAL or your condition speak to your doctor, nurse or pharmacist.



Temodal[®]
temozolomide
capsules 

This booklet is very important to me. If found, please return to:

Name: _____

Address: _____

Phone number: _____

Emergency contact name: _____

Emergency contact phone number: _____

Important contacts:

General practitioner

Name: _____

Phone: _____

Oncologist

Name: _____

Phone: _____

Nurse

Name: _____

Phone: _____

Neurosurgeon

Name: _____

Address: _____

Phone: _____

Radiation oncologist

Name: _____

Phone: _____

Other

Name: _____

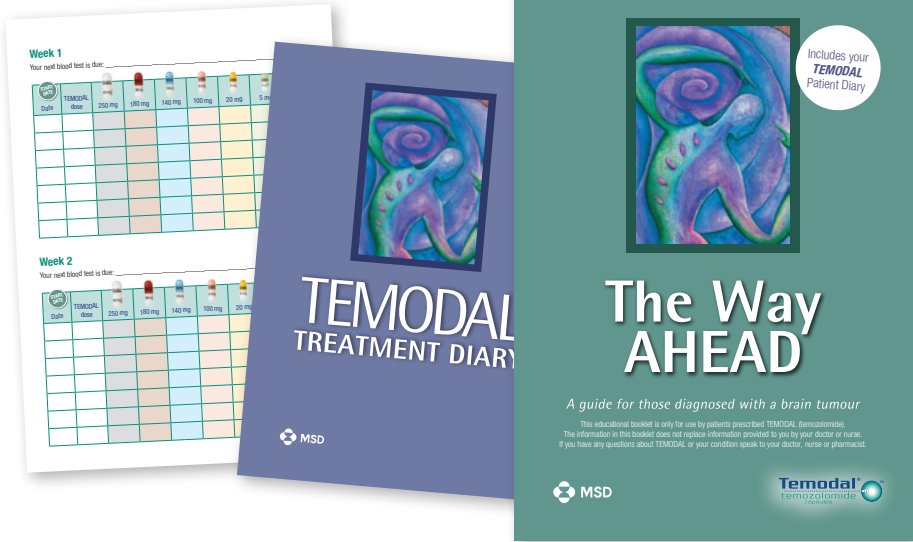
Phone: _____

Poisons Information Centre 13 11 26

Important notice: The information provided in this booklet does not replace any of the information or advice provided by a medical practitioner and other members of your healthcare team. If you have any further questions about Temodal or brain tumours, please contact your doctor.

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Special thanks and acknowledgment to Marina Kastelan, RN MN Nurse Practitioner, Neuro Oncology, Sydney Neuro Oncology Group, for her valued contribution to this resource.

Introduction

Being diagnosed with a brain tumour can be a traumatic, confusing and challenging experience. This booklet provides information about the condition and what you may expect on a day-to-day basis. It has been developed to help you understand the facts about brain tumours and what to expect from treatment and beyond. The aim is to give you supportive, practical information to complement and reinforce the information you will receive from your healthcare team. In these pages, you will find information on:

- your type of brain tumour
- its symptoms
- surgery
- radiotherapy
- chemotherapy
- managing the tumour's effects
- suggested questions to ask your healthcare team
- links to websites, resources and support organisations.

This booklet also includes a patient diary, to help you track and understand your treatment.

How to use this booklet

There is a lot of information in this booklet. Rather than tackle it cover to cover in one sitting, you may like to read a chapter a day or choose the information that is relevant to you at a particular point in time.

Remember that you are not alone. Make use of the support of your healthcare team, your family members and friends and the many other resources and organisations available to you.

SECTION 1

The Facts On Brain Tumours

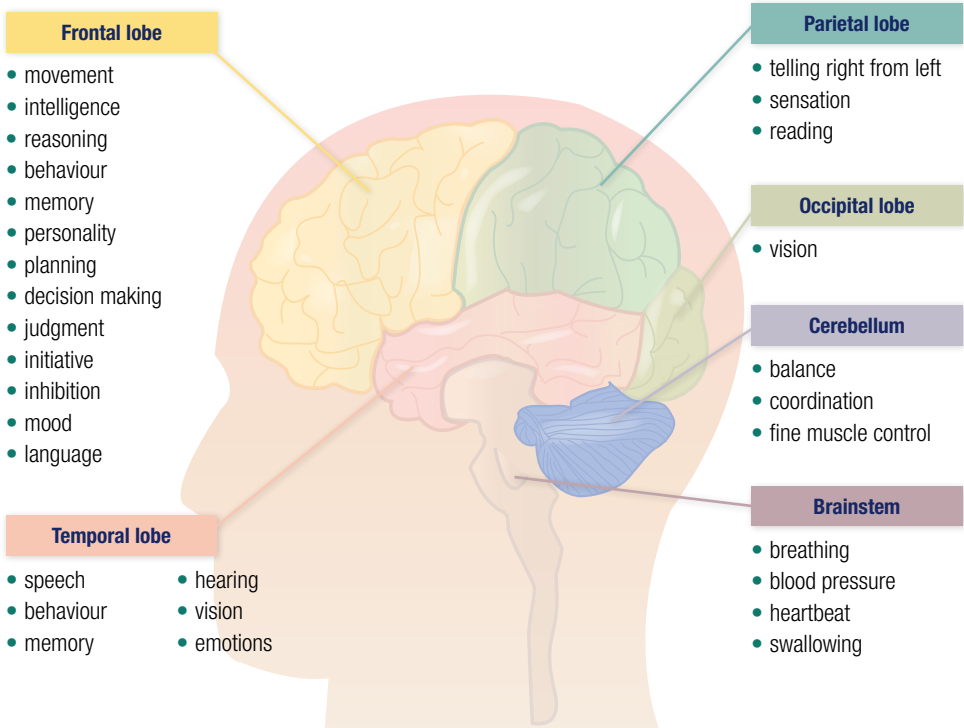
When you were first diagnosed, your doctor may have explained what type of tumour you have and where it is located. It is a lot to take in. You are not alone if you find the medical terminology complicated and confusing. On the following pages you will find the basic facts about your condition, which you can read and absorb in your own time.

What is a brain tumour?

A brain tumour is defined as any abnormal or uncontrolled growth of cells in the brain. It can be benign (non-cancerous) or malignant (cancerous). It is called a **primary brain tumour** when the tumour originates from the cells in the brain itself rather than travelling from another location in the body (secondary cancer).¹

A tumour is assigned a name and grade depending on what the tumour tissues reveal when examined under a microscope. The **type** of brain cell that the tumour arises from gives the tumour a name, for example an 'astrocytoma' originates from an astrocyte cell.²

The tumour is also assigned a **grade** depending on how the cancer cells look under a microscope and how quickly the tumour is likely to grow and spread. Usually, primary brain tumours are referred to as low-grade or grades I and II, while more active tumours are known as high-grade or grades III and IV.³

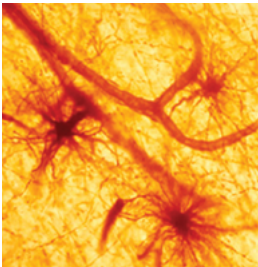


Common types of brain tumours

Gliomas

Gliomas are so named because they grow from glial cells which make up the supportive tissue of the brain—in other words they are the ‘glue’ of the brain which support the nerve cells (neurons).² Gliomas are the most common type of brain tumour accounting for about 70% of all primary malignant brain tumours (brain cancers).¹ Within the brain, gliomas usually occur in the hemispheres of the cerebrum (upper part of the brain) but may also affect other areas, especially the optic nerve, brainstem and cerebellum.⁴

There are three types of glial cells – astrocytes, ependymal cells and oligodendrocytes – and gliomas can arise from each of these cells (listed below).² Gliomas may also progress from a low-grade to a higher grade, or recur after surgery as a higher grade tumour.⁴



Anaplastic astrocytoma (grade III astrocytoma)

Astrocytomas arise from the type of glial brain cells called astrocytes—star-shaped supportive cells in the brain.² They can be located anywhere in the central nervous system (brain and spinal cord), but the most common location is the frontal lobe.⁵

An anaplastic astrocytoma (AA) is a grade III astrocytoma.¹ The word ‘anaplastic’ means malignant (cancerous).²

Glioblastoma multiforme (grade IV astrocytoma)

Another name for a grade IV astrocytoma is glioblastoma multiforme (GBM).¹ These are the most common type of malignant brain tumour in adults.³ This type of tumour contains cells that are very aggressive and rapidly invade nearby tissues. It usually develops in the cerebral hemispheres of the brain but it can be found anywhere in the central nervous system.²



Important point

High-grade glioma

*You may hear your doctor or members of your healthcare team refer to a ‘**high-grade glioma**’ which includes both anaplastic astrocytoma and glioblastoma multiforme.¹*

Will the brain tumour spread?

Most brain tumours do not spread outside the brain and spinal cord to another part of the body. If tumours do spread, this is known as a secondary cancer or metastasis. Most commonly, malignant tumours will recur locally but may spread within the brain to involve other regions. It is uncommon for the spinal cord to be involved.³

Who gets it?

Malignant brain tumours are less common than other types of cancer such as prostate, breast, bowel, melanoma, and lung cancer.¹

Brain tumours can happen at any age but anaplastic astrocytomas occur most commonly in people aged 30–50, while glioblastoma multiforme occur most commonly in those aged 50–70. Both are usually more prevalent in men.⁵

What causes a high-grade brain tumour?

A brain tumour occurs because of abnormal or uncontrolled growth of cells in the brain.

An established risk factor for a brain tumour is exposure to radioactivity (mainly through treatment to the head for other types of cancers).¹ Research is being conducted into other causes such as exposure to certain chemicals, genetic factors or infections.

There is no evidence to suggest it is due to anything you may or may not have done throughout your life, such as using a mobile phone.^{1,3}

Some people with certain rare genetic conditions may have a higher risk of developing a brain tumour. If you have a history of brain cancers in your family, you should raise this with your family doctor.¹

Possible symptoms

Brain tumours often invade or spread into normal brain tissue, causing pressure and symptoms such as nausea, seizures, vomiting, dizziness or leg and arm weakness.^{1,3} The symptoms may relate to the location of the tumour itself or may be due to areas of swelling around the tumour.¹ The type of symptom depends on the tumour's location and a person can experience many different kinds of symptoms. Alternatively you may not have any symptoms or only minor symptoms for a very long time.¹

Common symptoms may include:¹

- Headaches (which may become persistent and be worse first thing in the morning)
- Nausea and vomiting
- Personality changes (e.g. becoming angry more easily, being less sensitive to other people's problems, poor judgement when making decisions)
- Problems with thinking, memory and reasoning
- Seizures
- Other symptoms of nerve damage (e.g. vision problems, weakness on one side of the face or body, problems with speech, or difficulty performing everyday tasks like dressing).

You may experience other symptoms apart from those listed above.

See SECTION 4 for some practical ways of managing some of the more common symptoms.



Questions to ask your healthcare team

- What type and grade of brain tumour do I have?
- Where is the tumour located in my brain?
- What is my prognosis?
- How can I reach you or someone else in your office if I have further questions?
- Are there other ways for me to obtain help?

Further information

Australia

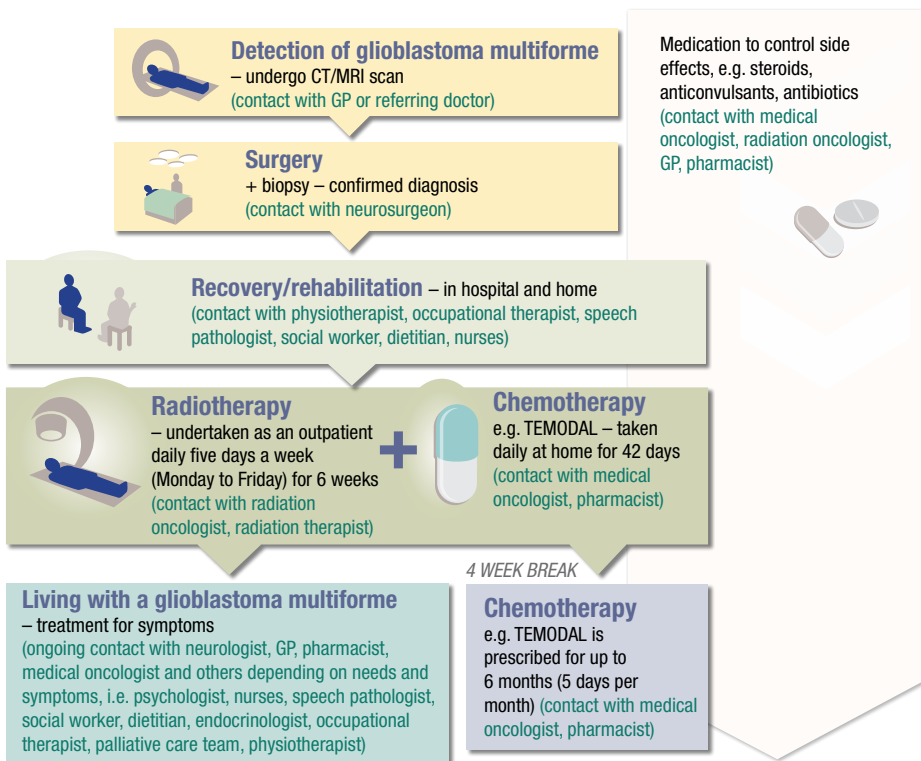
- Brain Foundation – www.brainfoundation.org.au

SECTION 2

Treating High-Grade Gliomas

Treating anaplastic astrocytoma and glioblastoma multiforme will involve a number of healthcare professionals working together as part of a multidisciplinary team. Treatment is necessary to control the tumour growth. Standard treatment includes surgery, radiotherapy and chemotherapy, and may include medications to control any side effects.³ You may be offered the option of participating in a clinical trial.

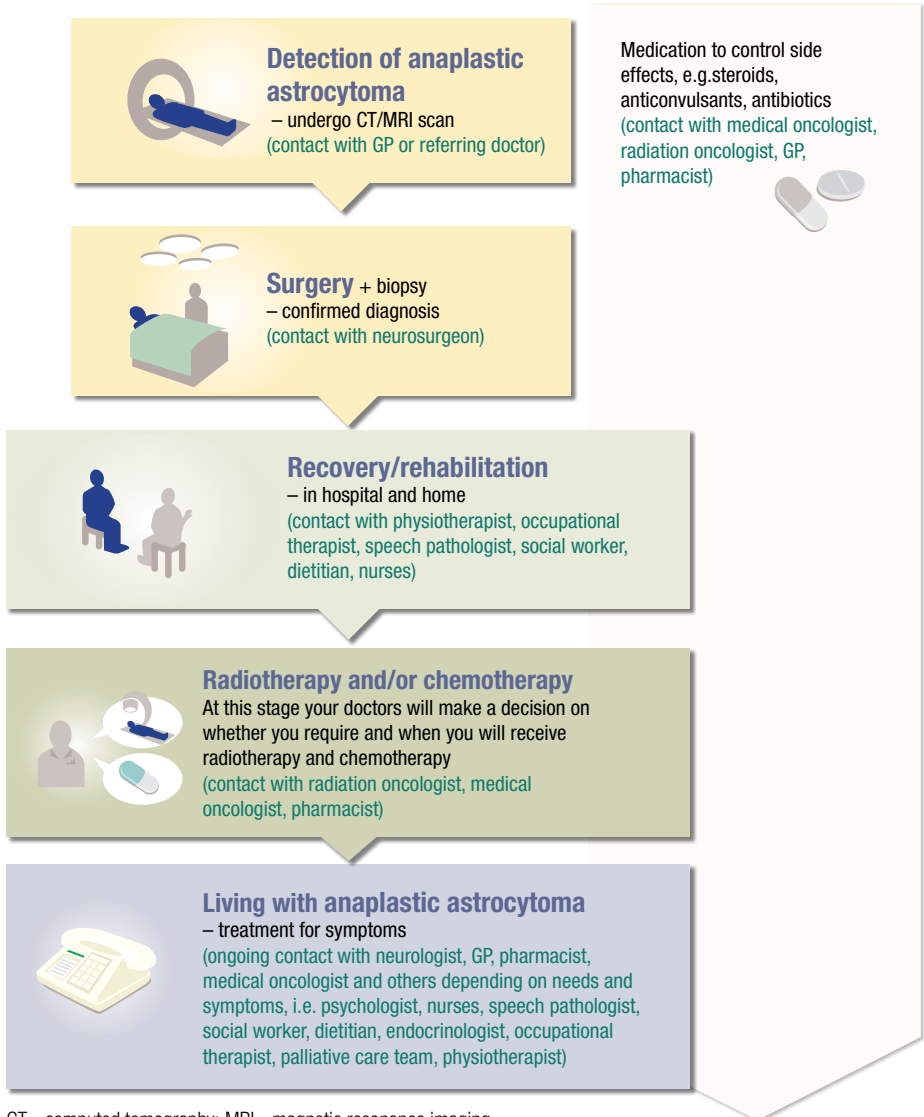
The following graphics give you an idea of what may occur in each treatment stage for either anaplastic astrocytoma (AA) or glioblastoma multiforme (GBM), and which member of your healthcare team will be your main point of contact during each stage. For glioblastoma multiforme, you will most probably undergo radiotherapy and your first stage of chemotherapy during the same period of time.¹ With an anaplastic astrocytoma, chemotherapy usually follows the radiotherapy treatment phase.¹ Your situation may be different so talk to your healthcare team and ask them to explain your individual treatment pathway.

Typical treatment pathway for a newly diagnosed glioblastoma multiforme^{1,3,6-9}

CT= computed tomography; MRI= magnetic resonance imaging.

Adapted from Cancer Council Australia (2011)¹, (2016)³ and (2016)⁷, TEMODAL Product Information⁸, Stupp *et al.* (2014)⁹, and Stupp *et al.* (2005)⁶.

Typical treatment pathway for anaplastic astrocytoma^{1,3,8}



CT= computed tomography; MRI= magnetic resonance imaging.

Adapted from Cancer Council Australia (2011)¹, (2016)³ and Stupp *et al.* (2014)⁸.

What happens if the tumour recurs (or continues to grow)?

If the brain tumour recurs or progresses after treatment (surgery, radiotherapy, chemotherapy), your doctors may consider other options including further surgery and/or chemotherapy treatments. Your doctor may also suggest that you take part in a clinical trial, which involves testing a new or modified treatment.¹

Diagnosis

After a neurological examination to assess physical and mental function, scans are usually ordered. Some of the different types of scans include:

- **Computed tomography scan (also known as a CT or CAT scan):**¹ A CT scan is a special type of X-ray that takes a three-dimensional picture of any part of the body using a computer.³
- **Magnetic resonance imaging (MRI):**¹ An MRI scan uses a powerful magnet to provide clear and detailed images of the structures and organs of the body.³
- **Magnetic resonance spectroscopy (MRS):** This is usually done as part of an MRI and is used to determine the level of different chemical components within tissues to help differentiate between normal tissue and tumour.³
- **Positron emission tomography (PET):** This involves injecting a radioactive tracer solution, which is absorbed by cancer cells at a faster rate than normal cells and highlights the active cells.³

These scans will be used to determine the location and size of the tumour, which are important considerations for surgery.¹

As it is difficult to make a diagnosis from scans alone, a biopsy—where a small sample of tissue is taken—may be required to confirm the tumour type.¹

See SECTION 3 for information about healthcare professionals that may play a role in your treatment, rehabilitation and care.

Surgery and radiotherapy

Different treatment options are available for high-grade gliomas, and your doctor will help you to decide on the best treatment choice for you.

As a general guide:

- The first step in therapy may involve surgery to remove as much of the tumour tissue as possible while minimising damage to normal brain tissue.³
- As it is impossible to remove all the microscopic tumour cells during surgery, it is important to have extra treatment in the form of radiotherapy and chemotherapy.³



About TEMODAL®

TEMODAL is used to treat high-grade gliomas.⁶ It interferes with cell growth, especially in cells that are growing rapidly such as tumour cells.¹⁰ TEMODAL has been studied in large scientific trials.⁶

How does TEMODAL work?

TEMODAL is absorbed from the gut and, once in the bloodstream, is converted into an active form.⁶

This active form of TEMODAL is able to cross from the blood into the brain cells (blood–brain barrier) and attack your cancer.⁶ TEMODAL is able to act directly on the DNA in the cells in your body.¹¹ DNA controls the growth of normal cells as well as brain tumour cells. Because these tumour cells grow much faster than normal cells, they are affected by TEMODAL to a much greater extent.¹²

The response to treatment can vary between individuals.

TEMODAL is able to cross from the blood into the brain cells (blood–brain barrier) and attack your cancer.⁶

How do I take TEMODAL?

Newly diagnosed glioblastoma multiforme¹⁰

You will usually have TEMODAL in combination with radiotherapy. Your doctor will usually start you on TEMODAL **every day for 42 days**. This is the first part of the treatment ('concomitant' or 'concurrent' phase), which will coincide with six-weeks of radiotherapy. Treatment will then be interrupted for **four weeks** to give your body a chance to recover. After this break, your doctor will begin the next phase of your treatment (the 'adjuvant phase') and your TEMODAL dose will change. In this phase there are up to six treatment cycles. Each treatment cycle lasts 28 days. You will take TEMODAL daily for five days and then take a break from taking TEMODAL for 23 days. After that the next cycle of five days with TEMODAL, then 23 days without TEMODAL begins. And so on for a further four 28-day treatment cycles (i.e. six cycles). Before each new treatment cycle begins, your blood will be tested to determine if the TEMODAL dose needs to be adjusted.

Recurrent anaplastic astrocytoma or recurrent glioblastoma multiforme^{10,13}

Usually, you will take TEMODAL daily for five days and then take a break from taking TEMODAL for 23 days (28-day cycle). After that, the next cycle of five days with TEMODAL, then 23 days without TEMODAL begins. And so on for a further four 28-day treatment cycles (i.e. up to six cycles). Before each new treatment cycle begins, your blood will be tested to determine if the TEMODAL dose needs to be adjusted.

Treating newly diagnosed glioblastoma multiforme with TEMODAL^{6,14}

Concomitant Phase – 6 WEEKS

Radiotherapy	R	R	R	R	R	R				RADIOTHERAPY – conducted as an outpatient daily five days a week (Monday to Friday) TEMODAL – oral capsule taken daily (7 days a week) <i>This weekly cycle is undertaken 6 times</i>
TEMODAL	T	T	T	T	T	T	T	T	T	
Day	1	2	3	4	5	6	7			

**End of radiotherapy and initial TEMODAL treatment
4 week break**

Adjuvant Phase – 28 DAY Cycle For 6 Months

Day 1	T	T	T	T	T				TEMODAL only for 5 days No TEMODAL for 23 days Day 28

Blood test

Dosage may or may not be adjusted

The 28 day cycle may be repeated a further 5 times
(i.e. 6 cycles over 6 months) – length of treatment may be individualised

Treating recurrent anaplastic astrocytoma and recurrent glioblastoma multiforme with TEMODAL⁶

28 DAY Cycle

Day 1	T	T	T	T	T				TEMODAL only for 5 days No treatment for 23 days Day 28

Blood test

Dosage may or may not be adjusted

The 28 day cycle may be repeated a further 5 times
(i.e. 6 cycles over 6 months)

How much to take¹⁰

TEMODAL comes as different strength capsules (shown on the outer label in mg) and are dispensed in individual foil packs. Each strength is a different colour to help with identification. Depending on the dose of TEMODAL your doctor prescribes, you may have to take several capsules on each dosing day of the treatment cycle. Your medical oncologist will decide on the most appropriate dose by initially assessing your height and weight.⁶ Subsequent dosage adjustments will be based on the results of your blood cell counts and any side effects you may be experiencing.⁶



Plan to take TEMODAL on an empty stomach at least one hour before a meal in order to maximise the body's ability to absorb the medication. Take each day's dose at one time. Be sure that you swallow the capsules whole with water. TEMODAL is used best by your body if you take it at the same time every day in relation to a meal.

What are the likely side effects of TEMODAL?¹⁰

Tiredness, constipation, nausea and vomiting are among the most common side effects associated with TEMODAL. Your medical oncologist can prescribe medicines that may help reduce some of these effects. Other common side effects include headache, loss of appetite or weight, diarrhoea, fever or high temperature, rash, hair loss, itching, dizziness, weakness, general body pain, stomach pain, indigestion, different taste sensation, mouth ulcers, coughing, and sleeplessness.

Tell your doctor if you notice any of the following:

- Shortness of breath
- Tingling or numbness in hands or feet
- Bruising, bleeding or being unusually pale or tired
- New or recurring infections
- Symptoms of diabetes (including passing a large amount of urine and constant thirst)
- Shivering associated with chills and fever
- Development of red or purple spots under the skin.

These may be serious side effects, and you may need medical attention.



Important point

Capsule or intravenous drip

Taking chemotherapy in capsule form at home can be just as effective as having it through an intravenous drip (IV) in hospital.¹⁵ TEMODAL is not available through an intravenous drip.⁶

Swallowing capsules²²

Many people have trouble swallowing capsules. You might like to try the following:

- Practice swallowing small lollies such as tic tacs® or M&Ms® or small bites of food without chewing. This will help you get used to swallowing pills.²²
- Take a deep breath before placing the capsule in your mouth. This may help suppress the gag reflex.
- Lean forward once you have placed the capsule in your mouth. The capsule will float to the back of the mouth and into a good position for easy swallowing.
- Drink a whole glass of cold water while swallowing the pill.

For patients on TEMODAL plus radiotherapy, your doctor may prescribe an antibiotic to help your body fight infection because TEMODAL may lower your body's white blood cell count (reducing your natural defence against infection).¹

While taking TEMODAL, and for six months afterwards, both male and female patients and their partners should use effective contraception.⁶ TEMODAL may cause infertility in men, therefore men may wish to consider storing sperm in a sperm bank before starting chemotherapy.⁶

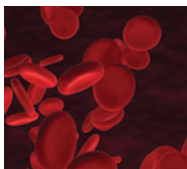
Managing chemotherapy side effects

Constipation – TEMODAL may cause constipation.¹⁰

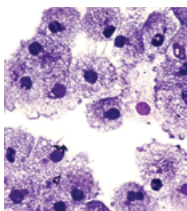
Helpful hints for constipation

- Let your doctor know if you experience constipation as they may prescribe medication or recommend over-the-counter medication such as laxatives or a stool softener to relieve it.¹
- Eat more high-fibre foods, such as wholegrain bread and pasta, nuts, bran, fresh and dried fruit and raw or cooked vegetables.
- Drink plenty of fluids, especially water and fruit juices. Hot and warm fluids may also help.

Other possible side effects of TEMODAL



Red blood cells carry oxygen around the body. TEMODAL can cause a drop in red blood cells (anaemia), which may require medical treatment.^{6,11}



White blood cells play a major role in the body's defence against infection. TEMODAL may affect your white blood cell count.⁶ Your doctor may prescribe an antibiotic to help prevent infection.¹

Platelets assist with blood clotting and preventing bleeding. Platelets may be affected by TEMODAL, and treatment may need to be altered if the platelet count drops too low.⁶



Important point

Repeat prescriptions

Your medical oncologist may supply you with a prescription for an initial course of TEMODAL plus repeat prescriptions. It is recommended that you do not fill out your repeat prescriptions upfront as your dose may change before your next treatment cycle. Your medical oncologist will advise you when to have your prescriptions filled. Alternatively, you could ask your pharmacist to file these repeat prescriptions for you until you are ready to have them filled.

Please note that both TEMODAL and radiotherapy may cause fatigue, nausea and vomiting, and hair loss.^{7,10}

TEMODAL Dos and Don'ts ^{6,10}

DO ✓	DON'T ✗
<p>Do take TEMODAL on an empty stomach at least 1 hour before a meal.</p>	<p>Don't open or split the capsules. If the capsules are accidentally opened or damaged, you should be extremely careful to avoid inhaling the powder in the capsules or getting it on your skin or in your nose or mouth.</p>
<p>Do contact your doctor or call the Poisons Information Centre on 13 11 26 if you accidentally take more capsules than you are supposed to.</p>	<p>Don't chew the capsules. TEMODAL capsules should always be swallowed whole.</p>
<p>If you miss a dose, do take the missed dose as soon as possible during the same day. If a full day has gone by, do not take a double dose unless your doctor tells you to do so. Tell your doctor at your next appointment.</p>	<p>If vomiting occurs after you take your capsules, don't take another dose that day. Tell your doctor at your next appointment. If vomiting persists, contact your doctor.</p>
<p>Do tell your doctor if you are taking any other medicines.</p> <p>These include medicines that you buy without a prescription from a pharmacy, supermarket or health food shop. Some medicines may affect how well TEMODAL works.</p>	<p>While you are taking TEMODAL, you or your partner should not become pregnant. TEMODAL may cause birth defects so birth control and wearing a condom is strongly recommended during the time you are taking TEMODAL and for 6 months after stopping.</p>

TEMODAL checklist



- Do you understand exactly how many capsules you need to take of each strength? Ask your doctor or pharmacist to write down the number of each strength capsule you need to take each dosing day.
- Do you know exactly which days are your dosing days? Mark them down on a calendar or in your *TEMODAL Treatment Diary*.
- Be sure to review the dose with your doctor each time you start a new cycle. Sometimes the dose or the mix of capsules you need to take will be different from the last cycle.
- If you are confused or unsure about how to take your dose, speak with your doctor or pharmacist immediately – before you take the medicine home.
- Don't fill your prescription repeats without discussing the dose with your medical oncologist. Your dose may change before your next treatment cycle begins.

Other medications

Your doctor may also prescribe the following medications to assist with any side effects and/or symptoms:¹

- **Antibiotics** – to help your immune system fight or prevent infections which may be affected by the chemotherapy
- **Steroid drugs** (e.g. dexamethasone) – used to reduce the swelling that often surrounds brain tumours before or after surgery or radiotherapy. Side effects may include increased appetite and weight gain, muscle weakness, skin thinning, emotional changes, sleep disturbances and the possibility of steroid-induced diabetes.^{16,17} Ask your doctor for more information. Also see ‘Helpful hints’ below
- **Anticonvulsant medication** – used to treat seizures. For more information on seizure management, see pages 23–25
- **Antinausea medication** – to help combat any nausea you may experience from the chemotherapy or radiotherapy
- **Laxatives and/or stool softeners** – to help with any constipation (sometimes antinausea medication can make constipation worse).

If you are allergic to any medications, please discuss this with your doctor.

Helpful hints for managing steroid side effects¹⁷

- To reduce the effects of insomnia (trouble sleeping), take your steroid tablets in the morning after food.
- If you experience an increased appetite, try to stick to a healthy diet. A dietitian will be able to give you advice, however some weight gain usually occurs while taking steroids.
- You may experience muscle weakness in the upper arms and legs that may make activities such as climbing stairs or getting out of a chair more difficult. A physiotherapist will be able to advise on appropriate exercises to help.
- Steroids may cause mood swings, personality changes, anxiety and irritability. If you are experiencing these, talk to your doctor.



Important point

Safety of radiotherapy and chemotherapy

You will not ‘glow in the dark’, be ‘radioactive’ or contagious in any way. You can still interact with others, including children, babies, and pregnant women without causing them any harm.⁷

However, it usually takes around seven days after your TEMODAL treatment to eliminate all the chemotherapy from your body via your body fluids, e.g. urine, bowel motions, vomit, semen, and vaginal fluid.¹⁵ It is important to protect others who live with you by:¹⁵

- always flushing the toilet with the lid down after you have used it
- advising your loved ones to wear gloves when they are in contact with your bodily fluids, e.g. cleaning up bodily fluids, vomit etc.
- using a condom (even if you or your partner are on another form of contraception).

Questions to ask your healthcare team

- Ask your surgeon how much of the tumour was removed during surgery. How much remains?
- Ask your surgeon where the remaining tumour is located. Why couldn't it be removed?
- What factors will you look at to predict how I am going to do?
- When do I have a follow-up appointment with my neurosurgeon?
- How often will I see the medical oncologist and radiation oncologist?
- What are the risks and possible side effects of each treatment?
- After I finish radiotherapy, how long will the side effects last?
- Is there anything else I can do to reduce side effects?
- Should I be on a special diet?
- How long will I be on chemotherapy?
- How much will the treatments cost?
- Which issues should I ask my medical oncologist about and which ones should I discuss with my GP?



Further information

Further information/General treatment information

- Cancer Council. Understanding brain tumours – www.cancer.org.au/content/about_cancer/ebooks/cancertypes/Understanding_Brain_Tumours_booklet_May_2016_revised.pdf
- Cancer Council. What to expect – High grade glioma – www.cancer.org.au/content/ocp/what-to-expect-high-grade-glioma-2016.pdf

Radiotherapy

- Cancer Council. Understanding radiotherapy – www.cancer.org.au/content/about_cancer/treatment/Understanding%20Radiotherapy_booklet_January%202016.pdf
- Trans Tasman Radiation Oncology Group – www.trog.com.au

Look Good...Feel Better

- Managing appearance-related side effects – www.lgfb.org.au

Further information/Managing symptoms and change

- Memory loss – <http://snog.org.au/wp-content/uploads/2016/11/Memory-2016.pdf>

TEMODAL

- TEMODAL consumer medical information – www.medicines.org.au/files/mkctemod.pdf

Wigs

- Cancer Council – Ph 13 11 20; www.cancer.org.au – Many of its state offices offer a wig lending service.
- Your treatment centre may also offer a wig lending service.

SECTION 3

Working With Your Healthcare Team

As discussed in SECTION 2, your core healthcare team of neurosurgeon, medical oncologist and radiation oncologist plus many others are involved in your care is what is known as a multidisciplinary team. While this is the best approach to support you and coordinate your individual treatment plan, it may be difficult to remember who is in charge of which area and who is the best person to answer your questions. This section will introduce you to some key members of your healthcare team and give you some ideas and tips on communicating with them to ensure optimal care.

Your healthcare team

General practitioner (GP) – refers you to other specialists where appropriate. They will be responsible for your ongoing care and may prescribe medication for any symptoms or side effects. Many specialists will send your GP an update of your progress.

Neurologist – a doctor who specialises in the diagnosis and treatment of diseases and disorders affecting the central nervous system (CNS). They are responsible for the ongoing management of seizures.

Neurosurgeon – a surgeon who specialises in the diagnosis, treatment and surgical management of disorders of the central nervous system. Following surgery, you will probably have a follow-up appointment with your neurosurgeon to check test results and assess how you are recovering. Unless further surgery is deemed necessary, you may or may not have any ongoing contact.

Medical oncologist – a doctor who specialises in the medical management of cancer who will oversee your chemotherapy treatment. After completing treatment regular monitoring and assessment will continue. You may be offered further chemotherapy of a different type.

Neuro-oncologist – a doctor who specialises in diagnosing and treating brain tumours and other tumours of the nervous system.

Radiation oncologist – a doctor who specialises in the delivery of radiation therapy. Your radiation oncologist will continue to regularly monitor you while you are undergoing radiotherapy—usually once a week.

Radiation therapist – a technician who will prepare you for radiotherapy, and communicate with you and monitor you throughout the procedure.

Nurse – supports and assists you through your treatment and recovery and can assist in coordinating services and support.

Pharmacist – dispenses your medicines and checks for drug interactions, advises on possible side effects, and also discusses the best way to take the medicine.

Other important team members

Rehabilitation is a very important part of the treatment plan. The goals of rehabilitation depend on your needs and how the tumour has affected your daily activities.

The following is a list of some other key healthcare professionals who you may consult depending on your symptoms and needs.

Endocrinologist – closely monitor hormones and a consultation may be needed if your blood glucose level rises (or existing diabetes becomes more difficult to manage).

Occupational therapist – assesses a person's ability to manage daily tasks and recommends any home modifications or physical aids (such as a wheelchair or shower rail) that may be needed. They may help to overcome any difficulties with eating, dressing, bathing and using the toilet as needed.

Palliative care team – usually provided by a doctor and/or nurse in hospital or at home. The aim of palliative care is to manage symptoms and provide physical, psychological, social and spiritual support.

Physiotherapist – works on a person's ability to move, coordinate and balance. If an arm or leg is weak or paralysed, or in the event of problems with balance, physical therapy may be necessary.

Social worker – assists people with locating useful community and government services and provides advice on welfare benefits, childcare, legal and financial support services and counselling.

Speech pathologist – help people overcome problems with speaking, expressing their thoughts, and swallowing.

Dietitian – provide advice on good nutrition and the most appropriate diet for those recovering from surgery and who are coping with medication/therapy effects.

Neuropsychologist – assesses how cognitive functions may have changed and suggest strategies to help manage any changes.



Communicating with your healthcare team

Medical appointments can be both overwhelming and stressful. You may feel that everything is happening so fast and that you do not have time to think things through. There are four crucial things that you can do that will help you communicate with your healthcare team.

1. Gather as much information as you can about your type of brain tumour and your treatment process. The more you understand, the better prepared you will be to ask questions, understand the role of each healthcare team member, and make treatment decisions.

2. Write everything down. Dedicate a specific exercise book or journal to record your questions, concerns and main points from each appointment.

3. Take someone with you when you go to medical appointments. There is a huge amount of information to take in and it can help to have a 'second pair of ears' to help you remember the main points and ask questions.

4. Don't be afraid to ask questions. If you don't understand a particular terminology or process, interrupt your specialist nurse or doctor and ask them to explain it to you again more slowly or in a different way such as with a diagram so that you understand.

Helpful hints for communication

- At times you may feel angry or upset. Ask for what you want clearly and directly.
- If you have lots of questions, ask your specialist nurse or doctor to schedule a longer appointment next time or ask when you can talk on the phone about your immediate questions. The reality is that specialist nurses and doctors are busy people and have many patients to see but it is also your right to have your questions answered and not to feel like you are being rushed out the door.
- Prioritise your questions so that the important ones get answered first in case you run out of time.
- Make appointments for the time of day when you are most alert.



Who to contact in an emergency

Share this information with your family members and friends. This table describes who you should contact in different situations. The symptoms that are coloured red require immediate action; orange requires some follow-up and green is less serious and can be mentioned to your doctor at your next visit.

	What happens if I experience the following?	Action required (in order of priority)	Contact details (fill these in yourself)
Call an ambulance¹	Seizures – If: <ul style="list-style-type: none"> • you have not had a seizure before • you are injured during a seizure • it lasts more than 5 minutes • second seizure starts before you have completely recovered from the previous seizure • you have repeated generalised seizures within a 24-hour period • not awake and aware of your surroundings within 10 minutes of a seizure. 	Call for an ambulance on 000	Emergency Services contact: 000
Urgent medical attention needed	Side effects – If you experience: ¹⁰ <ul style="list-style-type: none"> • shortness of breath • tingling or numbness in hands or feet • bruising, bleeding • symptoms of diabetes (e.g. passing large amount of urine and constant thirst) • shivering associated with chills and fever • red or purple spots develop under the skin 	These may be serious side effects – contact your specialist nurse or doctor as soon as possible, you may need to go to hospital.	Nearest Accident and Emergency Department
	Medications – If you: ¹⁰ <ul style="list-style-type: none"> • take too much of any medication (including TEMODAL) 	Immediately telephone your specialist nurse or doctor or Poisons Information Centre Do this even if there are no signs of discomfort or poisoning.	Poisons Information Centre contact: 13 11 26
Tell your doctor or pharmacist	Side effects – If you: ¹⁰ <ul style="list-style-type: none"> • become unusually pale or tired • experience blood clotting problems • experience frequent infections • have any other symptoms that worry you 	General practitioner Pharmacist	
	TEMODAL – If you: ¹⁰ <ul style="list-style-type: none"> • feel sick or vomit while being treated with TEMODAL 	General practitioner Pharmacist	

Summary – Working with your healthcare team

1. There are many healthcare professionals available to assist you with your ongoing care and rehabilitation.
2. Find out as much as you can about your particular type of brain tumour and your treatment so that you will be able to better understand and manage your symptoms.
3. Ask lots of questions.
4. Dedicate a specific exercise book or journal to record your questions, concerns and main points from each appointment and take someone with you when you go to medical appointments.

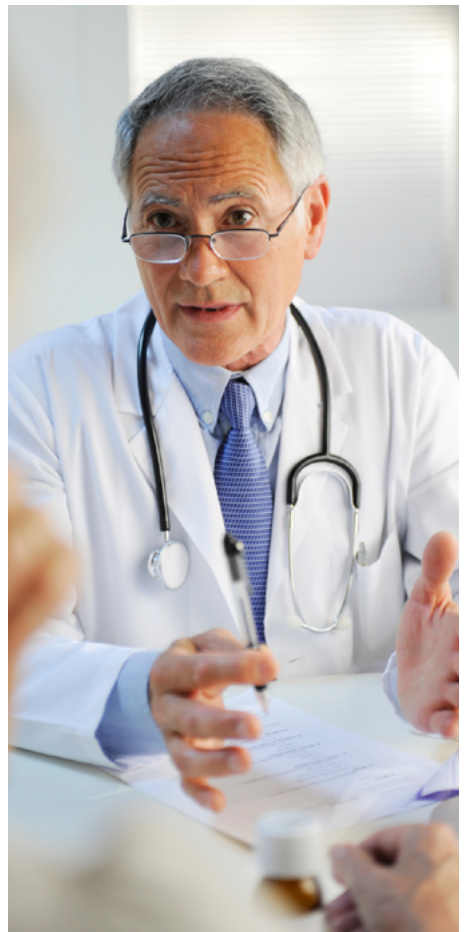
Questions to ask your healthcare team

- What follow-up tests should be done after my radiotherapy and chemotherapy? How often will these be done?
- Are there any other healthcare professionals that you think I would benefit from seeing?
- How do I contact you in an emergency?
- Who should I contact after hours?
- Are there any situations when I should go straight to the hospital or call an ambulance?



Important point Follow-up appointments

At the end of each appointment, get into the habit of asking your healthcare professional: 'What happens next?'. Also find out if and when the next appointment will be and how that will be done (i.e. automatically done for you or will you need to make the booking?). Record this information in your journal.



SECTION 4

Managing Symptoms And Changes

Being diagnosed with a high-grade glioma affects your life in many ways. You may be managing daily physical changes but also coping with varying emotions, anxiety and stress that you will naturally feel. In this chapter, we explore how you may be able to manage the impact of any physical and cognitive (thinking/reasoning) changes and some of the other emotional and social changes that you may face on a day-to-day basis.

Managing common symptoms

It is estimated that more than half of all patients with high-grade brain tumours experience some cognitive or behavioural change.¹⁸ Following treatment, you may be aware of changes in the way you feel, think, remember and act. These changes may be so subtle that only you will notice them. At other times, it will be those closest to you who will first see these differences and you may not be aware of them.¹⁸

A number of factors cause changes in brain functioning including the location, size and how fast the tumour grows. It may also be affected by your surgery and/or your subsequent radiotherapy and chemotherapy.¹⁸ In fact, it may be difficult for your doctors to determine whether any changes are due to the tumour or the treatment.

These patterns of changes vary considerably from person to person. Some of the more common physical, emotional and social changes you may experience are listed below, but you may experience different or additional ones.

Seizures

Seizures may have different manifestations, but commonly you may experience twitching in the face, arm or leg without complete loss of consciousness known as a 'simple partial seizure'.² Alternatively you may become unresponsive or confused and lose contact with what's going on around you, known as a 'complex partial seizure'.¹⁹ Some may experience total body shaking with complete loss of consciousness (known as a 'generalised' or 'tonic-clonic' seizure).¹⁹

Helpful hints for seizures

- Inform family members, friends and co-workers of what to do if a seizure occurs (see below).
- After a seizure, you may be very tired so take time to rest.
- Be aware that speaking may be difficult so try not to become frustrated.
- Walking may be tiring due to limb weakness, so give yourself time to readjust.
- When showering or bathing you may require some supervision or assistance at times.
- Restrict strenuous physical activities, and be aware that some may require a medical reassessment before participation, e.g. SCUBA diving, abseiling.
- Participate in certain activities with a 'buddy' (e.g. swimming, bike riding) in case you need assistance.
- Limit alcohol consumption.
- An emergency bracelet or wallet/purse information card can provide valuable emergency information (see www.medicalert.org.au/)
- Discuss driving restrictions with your healthcare team.²⁰

How someone can help if you experience a seizure²⁰

- Remain calm and don't panic
- If possible do not leave me alone during the seizure
- Lower me to the floor and loosen any clothing if it is restricting my breathing
- Move or remove any items that might cause injury
- Do not restrain me in any way but protect me from hurting myself
- Move me onto my side to allow saliva to flow freely from my mouth
- Do not try to put anything in my mouth - this is a choking risk
- Seek medical assistance if a generalised seizure occurs longer than 3–5 minutes. Call 000.
- Seizures are exhausting, allow me a period of re-orientation and rest
- Notify the treating medical professional about the seizure

Short- and long-term memory loss

Helpful hints to assist memory²¹

- Write everything down in one place (a diary or whiteboard) while it is still fresh in your mind.
- Keep a large calendar that shows the day and date.
- Try to stick to a daily routine.
- Consult a speech pathologist and/or neuropsychologist who may be able to offer some rehabilitation or management advice.
- Write down information you want to discuss with your doctor to help organise your thoughts.
- Take a family member or friend with you to medical appointments.
- Keep detailed notes (as though writing information for someone else who doesn't know you to help understand it later on).
- Always keep your purse, wallet, glasses, keys etc in the same place.
- Keep lists on a notepad or whiteboard somewhere handy in your home.
- Only list five tasks on your 'to do' list. Try not to add another item to the board until you have completed one of the tasks already on the list.
- Try to break down difficult things to learn into small pieces so you can learn each little bit one at a time.
- Memorise little 'chunks' of information, e.g. breaking long phone numbers into smaller groups of three or four numbers.



Questions to ask your healthcare team

- What mental and physical changes should I expect based on my tumour location?
- Can I exercise and play sport?
- Do I need seizure medication?
- Will my behaviour be affected?
- Can I still drive?
- What if I am not coping and feel depressed?
- Can I still work?
- Am I eligible for any government assistance?



Further information

Seizures

- Epilepsy Australia – www.epilepsyaustralia.net
- Epilepsy Action Australia – www.epilepsy.org.au

Memory loss

- Sydney Neuro-Oncology Group – www.snog.org.au/wp-content/uploads/2016/11/Memory-2016.pdf

Coping strategies/depression

- The Cancer Council of Australia – Ph: 13 11 20; www.cancer.org.au

SECTION 5

Living With A Brain Tumour

In addition to the information and practical hints on managing and living with high-grade glioma mentioned previously, this section includes information on other ways that may help your quality of life and day-to-day stress. Also included is a checklist of ways that you can help yourself. The more you do for yourself, the more in control you will feel, which will contribute to a more positive frame of mind.

Support groups

Attending a support group or joining a telephone group (or linking to an email group via the internet) can offer mutual support and valuable information. Connecting with others who are in similar circumstances can assist in reducing the sense of isolation and they may also be able to offer practical suggestions and coping methods. Your state Cancer Council will be able to put you in touch with others (see details at the back of this chapter). Your treating hospital may also have their own support group, so ask your doctor or other members of your healthcare team.



Support from those closest to you

One of the most important thing you can do for yourself is accept offers of help. You don't have to go through this alone. Many people will ask: 'Is there anything I can do?' They will expect you to take the lead on this and tell them what you need. If you can't think of anything on the spot, make a list of tasks that others may help you with that you can discuss later on. If you don't feel comfortable about asking others for help yourself, ask a family member or friend to ask for you. Most people feel better and needed if they can offer some practical assistance. Perhaps you could put together a roster system (or ask one friend to coordinate this) and share the tasks around. Consider asking for the following:



- Help with driving you to and from your medical appointments and accompanying you when you meet with your doctors
- Housework tasks such as vacuuming, mopping floors, dusting, cleaning the kitchen, ironing, washing, gardening
- Preparing nutritious meals
- Doing the grocery shopping
- Looking after children, driving them to school and other activities
- Taking you out for a meal, movies, concert etc
- Doing some exercise with you, i.e. swimming, gentle walking, regular yoga class
- Gift ideas—massage, trip to the beautician, inspiring books
- Source and attend a local meditation course with you.

One of the most important thing you can do for yourself is accept offers of help.

Checklist – Helping yourself

Understand all you can about high-grade gliomas

- Educating yourself on the facts about anaplastic astrocytoma or glioblastoma multiforme is very important. It will give you a sense of control, help you ask the essential questions and, most importantly, will mean you will be in a better position to manage your condition on a daily basis.
- Ask your healthcare team lots of questions and make sure they answer in a way that you understand.
- Keep a journal/diary and write everything down: appointments; questions; a summary of each doctor's visit; scan results, etc.

Look after yourself – body and soul

- Stay positive. You may have heard this advice many, many times and realistically it is not possible to think positive thoughts all the time and that is not expected. You should honour all of your feelings even if it means feeling down (but not all the time). It will help you and everyone else around you if you maintain your sense of humour and enjoy your life, friends and family as much as possible.
- Laugh. Go to a comedy club, rent some comedy classics or catch up with a friend and reminisce about some of the funnier moments you have had together.
- Eat a wide range of nutritious foods. Good nutrition can help you cope better with treatment side effects, help the healing process and improve your body's immune system. Consult a dietitian early in your treatment.
- If you don't feel like eating, consider liquid nutritional supplements. Ask a dietitian or members of your healthcare team for more advice.
- Get plenty of rest and have naps when you need them. Don't feel obligated to anyone else. Put your needs first.
- Relax your housekeeping standards.
- Prepare simple nutritious meals.
- Limit alcohol.

Look after yourself – body and soul (continued)

- Ask others for help as much as you can and accept all offers without feeling any obligation.
- Talk about your feelings. If you don't want to open up to a friend or family member, try a counsellor or an anonymous on-line forum or phone service like Lifeline.
- Exercise regularly and do something you like doing. It may be hard to find the motivation but a short walk or swim each day, or a regular yoga or Tai Chi class will help with your health and overall wellbeing. Ask someone to go with you if you are struggling to achieve this.
- If you have religious faith, spend time praying or in some devotional activity. It may offer a little peace.
- If you are not religious, spirituality in other forms may help. 'Mindfulness' is the state of living in the present and not letting thoughts and worries about the future or past colour your ability to enjoy what you are doing in the present moment. Consider doing a meditation class or some other form of relaxation as a pathway to mindfulness and as a way of easing stress and anxiety.
- Contact your state Cancer Council or ask your healthcare team for some suggestions on what's being offered in your local area.
- Make time for doing the things that you enjoy. Book that long overdue holiday or visit friends or relatives.



Summary – Living with a brain tumour

1. A **support group** can connect you with others who are in similar circumstances who will be able to offer practical suggestions and coping methods.
2. **Accept offers of help** and don't be shy in asking for help when you need it.
3. There are numerous **organisations** and **government subsidies** which may be able to help you on a wide range of issues such as household tasks, travel costs and financial support.
4. **Look after yourself**—eat nutritious meals, do some gentle exercise regularly, do things that you like doing and limit stress through meditation or some other relaxation technique.

Questions to ask your healthcare team

- Can I go on holidays?
- Should I be on a special diet?
- Can I still exercise? What activities should I avoid?
- Do you know of any support groups I could join?
- How can meditation or other relaxation methods help?

Conclusion

The main point that we hope you will take from this booklet is that, whatever challenges you face living with and managing a high-grade glioma, there is support to help you through—it could take the form of your healthcare team, others with the same condition, the many support organisations, government assistance or your loved ones and friends. You are not alone!

Further information

Support groups

- The Cancer Council of Australia – Ph: 13 11 20; www.cancer.org.au/aboutcancer/patientsupport.htm
- Brain Tumour Alliance Australia – www.btaa.org.au/page/26/support-organisations
- Sydney Neuro-Oncology Group Brain Tumour Support Group – www.snog.org.au/support-group/about-our-group/

Glossary Of Terms

Astrocyte: One of the most common types of glial cell.²

Astrocytoma: Tumour forming from an astrocyte.²

Anaplastic astrocytoma (AA): Grade III astrocytoma.¹

Biopsy: The taking of a small sample of tissue.¹

Brain tumour: Any abnormal or uncontrolled growth of cells in the brain.¹

Central nervous system: Consists of the brain and spinal cord.¹

Cerebellum: Located at the back of the brain below the cerebrum. Controls balance, coordination and fine muscle control.⁵

Cerebrum: Upper part of the brain which includes the frontal, parietal, occipital and temporal lobes.⁵

Chemotherapy: The use of anticancer (cytotoxic) drugs that damage or destroy cancer cells.¹

Computed tomography scan (CT or CAT scan): A special type of X-ray that takes a three-dimensional picture of any part of the body using a computer.³

Craniotomy: An operation in which the skull cavity is entered by temporarily removing a piece of bone to gain access to the brain.³

Glial cells: Make up the supportive tissue of the brain.²

Glioblastoma multiforme (GBM): Grade IV astrocytoma.¹

Gliomas: A tumour that grows from glial cells which make up the supportive tissue of the brain.²

Grade III or IV brain tumour: Most malignant (cancerous) types of brain tumour.³

High-grade glioma: Term for both an anaplastic astrocytoma and glioblastoma multiforme.¹

Magnetic Resonance Imaging (MRI) scan: Uses a powerful magnet to provide clear and detailed images of the organs and tissues of the body.³

Malignant: Characterised by progressive and uncontrolled growth.¹

Medical oncologist: Specialises in and will oversee your chemotherapy treatment.³

Metastasis: Spreading of the cancer from one part of the body to another. Also known as a secondary cancer.³

Mixed glioma: Combination of an astrocytoma and an oligodendroglioma.²

Multidisciplinary team: Involves a number of healthcare professionals working together on a person's treatment and rehabilitation plan.³

Necrosis: Dead tissue.²

Neurologist: A doctor who specialises in the diagnosis and treatment of diseases and disorders affecting the central nervous system.³

Neurosurgeon: A surgeon who specialises in the diagnosis, treatment and surgical management of disorders and diseases of the central nervous system.³

Oedema: Tissue swelling.¹

Oligodendrocytes: A type of glial cell.²

Oligodendroglioma: Tumour forming from an oligodendrocyte.²

Prognosis: Probable outcome.¹

Radiation oncologist: A doctor who specialises in the delivery of radiation therapy.³

Radiotherapy: Uses radiation to kill cancer cells or injure them so they cannot multiply.⁷

Useful Contact Details

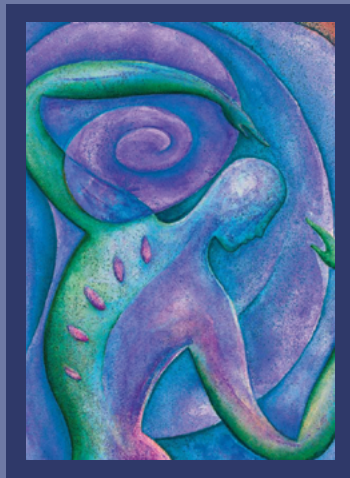
Brain tumour associations

Australia

- Brain Foundation – Ph: 1300 886 660; www.brainfoundation.org.au
- Brain Tumour Alliance Australia – Ph: 1800 857 221; www.btaa.org.au
- Sydney Neuro-Oncology Group – Ph: (02) 8425 3369; www.snog.org.au

Cancer councils

- The Cancer Council Australia – Cancer Council Helpline Ph: 13 11 20; www.cancer.org.au
 - ACT – www.actcancer.org
 - NSW – www.cancercouncil.com.au
 - NT – nt.cancer.org.au
 - QLD – www.cancerqld.org.au
 - SA – www.cancersa.org.au
 - TAS – www.cancertas.org.au
 - VIC – www.cancervic.org.au
 - WA – www.cancerwa.asn.au



TEMODAL TREATMENT DIARY

Introduction

The remaining pages of this booklet contain a diary, to help you track your TEMODAL treatment. This diary it does not take the place of talking to your doctor, nurse and pharmacist.

All medicines have risks and benefits. Your doctor has weighed up the benefits of you taking TEMODAL capsules against possible side effects it may cause. Everyone responds differently to treatment and, if you have any questions or concerns about taking TEMODAL capsules, discuss them with your healthcare team

The best way to use this diary

- Take it and use it every time you meet with, or speak to, a member of your healthcare team, e.g. appointments, phone conversations, obtaining medication at the pharmacy.
- Record your key contact numbers for quick reference.
- Work with your doctor and pharmacist to understand and record how many capsules of TEMODAL to take and how often, particularly noting dosage changes.
- Ensure your pharmacist dispensing TEMODAL is given the 'Pharmacy page' on page 36 in this diary so they can assist you with your treatment.
- Remember to take this diary with you when you go on holidays.

How to use this diary

Example only

These diary pages should be used only if you are taking TEMODAL in combination with radiotherapy

Take the prescribed dose of TEMODAL for exactly 42 days

Your doctor will fill out your details

Taking TEMODAL in combination with radiotherapy

TEMODAL & Radiotherapy

Number of capsules: **R R R R R**
T T T T T T T
 over 1 2 3 4 5 6 7
 This weekly cycle is undertaken 6 times
6 WEEKS

Ask your doctor to fill these details out for you.
 Take the dose indicated below every day for **42** days.
 (Note: your dose may change over this time period)

Daily instructions:
 Take TEMODAL first thing in the morning or evening on an empty stomach as directed by your healthcare professional.
 Please follow these steps:

- Step 1 Take **ondansetron** to prevent nausea & vomiting.
- Step 2 Wait **30-60 min**
- Step 3 Take TEMODAL capsules on an empty stomach, with water. Swallow capsules whole. Do not open or chew.
- Step 4 Wait one hour before having any food or taking medication. **60 min**

Week 1
 Your next blood test is due: **21/5**

Date	TEMODAL dose	250 mg	160 mg	140 mg	100 mg	20 mg	5 mg	Time (fill in)
12/3	20 mg							12pm
13/3	20 mg							12pm
14/3	20 mg							12pm
15/3	20 mg							12pm
16/3	20 mg							12pm
17/3	20 mg							12pm
18/3	20 mg							12pm

Week 2
 Your next blood test is due:

Date	TEMODAL dose	250 mg	160 mg	140 mg	100 mg	20 mg	5 mg	Time (fill in)

This means you would take one of the 100 mg capsules and one of the 20 mg capsules daily on an empty stomach

Insert the time of your radiation oncology appointment

These diary pages should be used if you are taking TEMODAL alone (i.e. not in combination with radiotherapy)

This is your daily dose. To make up this daily dose you may need to take a number of different strength capsules

Taking TEMODAL alone

TEMODAL only
 Day 1 **T T T T T**
No TEMODAL for 23 days
 Day 25
 This treatment cycle may be continued up to 6 months
Ongoing monitoring and individualised treatment

Ask your doctor to fill these details out for you.
 You will take TEMODAL for **5** capsules (1 cycle) over **28** days (the first 5 days you take TEMODAL, then the next 23 days no TEMODAL is taken).
 (Note: your dose may change over this period.)

Daily instructions:
 For the first 5 days of the cycle take TEMODAL first thing in the morning or evening on an empty stomach as directed by your healthcare professional.
 Please follow these steps:

- Step 1 Take **ondansetron** to prevent nausea & vomiting. **30-60 min**
- Step 2 Wait half an hour.
- Step 3 Take TEMODAL capsules on an empty stomach, with water. Swallow capsules whole. Do not open or chew.
- Step 4 Wait one hour before having any food or taking medication. **60 min**

Cycle 1
 Your next blood test is due:

Date	TEMODAL dose	250 mg	160 mg	140 mg	100 mg	20 mg	5 mg	Time (fill in)

Cycle 2
 Your next blood test is due:

Date	TEMODAL dose	250 mg	160 mg	140 mg	100 mg	20 mg	5 mg	Time (fill in)

This means you would take one of the 140 mg capsules and one of the 100 mg capsules daily on an empty stomach

TEMODAL is not taken for the next 23 days. Be sure to check your dose before starting the next cycle of treatment

Take your first dose on the day instructed by your doctor

Medication summary

Please tear out this page and give to your pharmacist dispensing
TEMODAL (To be filled in by your doctor)

Recommended pharmacy and contact person: _____

Name of patient: _____




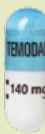
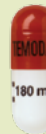

TEMODAL (tick where appropriate):

This is my patient's:

- First prescription of TEMODAL for the treatment of a high-grade glioma
- Second or subsequent prescription of TEMODAL
- The dose has changed from last prescription
- The dose has NOT changed from last prescription

My patient's current treatment:

Current dose: _____ mg daily for _____ days

-  5 mg
-  20 mg
-  100 mg
-  140 mg
-  180 mg
-  250 mg

Current treatment schedule

- TEMODAL in combination with radiotherapy – TEMODAL is taken every day for 42 consecutive days, followed by a 4 week break from any treatment
- TEMODAL alone – TEMODAL is taken once daily for five days followed by 23 days without treatment for 6 cycles (or 6 x 28 days)
- The dose may vary throughout treatment

Dosage and the number of each coloured capsule should also be recorded in the person's TEMODAL diary, starting on page 39.

Additional medications *(tick where appropriate):*

In addition to the TEMODAL chemotherapy, I have also prescribed:

_____, to prevent nausea and vomiting.

To be taken 30–60 min prior to taking TEMODAL.

_____, to prevent opportunistic infections.

To be taken at a dose of _____, on the following days:

_____, _____, _____.

_____, to reduce swelling and pressure.

To be taken as directed.

The current dose is: Stable Increasing Tapering

_____, to prevent seizures.

To be taken as directed.

_____, for constipation.

To be taken as directed.

Other _____.

Other _____.

Taking TEMODAL in combination with radiotherapy

TEMODAL & Radiotherapy

Radiotherapy	R	R	R	R	R		
TEMODAL	T	T	T	T	T	T	T
Day	1	2	3	4	5	6	7

This weekly cycle is undertaken 6 times

6 WEEKS

Ask your doctor to fill these details out for you.

Take the dose indicated below **every day** for _____ days

(Note: your dose may change over this time period)

Daily instructions

Take TEMODAL first thing in the morning or evening on an empty stomach as directed by your healthcare professional.

Please follow these steps:

Step 1 Take _____ to prevent nausea & vomiting.

Step 2 Wait 30–60 min

30–60 min








Step 3 Take TEMODAL capsules on an empty stomach, with water.
Swallow capsules whole. Do not open or chew.

Step 4 Wait one hour before having any food or taking medication.

60 min








Week 1

Your next blood test is due: _____

 START DATE	TEMODAL dose	 250 mg	 180 mg	 140 mg	 100 mg	 20 mg	 5 mg	Rad Onc appt time
Date	dose	250 mg	180 mg	140 mg	100 mg	20 mg	5 mg	








Week 2

Your next blood test is due: _____

 START DATE	TEMODAL dose	 250 mg	 180 mg	 140 mg	 100 mg	 20 mg	 5 mg	Rad Onc appt time
Date	dose	250 mg	180 mg	140 mg	100 mg	20 mg	5 mg	








Week 3

Your next blood test is due: _____

 START DATE	TEMODAL dose	 250 mg	 180 mg	 140 mg	 100 mg	 20 mg	 5 mg	Rad Onc appt time
Date	dose	250 mg	180 mg	140 mg	100 mg	20 mg	5 mg	appt time








Week 4

Your next blood test is due: _____

 START DATE	TEMODAL dose	 250 mg	 180 mg	 140 mg	 100 mg	 20 mg	 5 mg	Rad Onc appt time
Date	dose	250 mg	180 mg	140 mg	100 mg	20 mg	5 mg	appt time








Week 5

Your next blood test is due: _____

 START DATE	TEMODAL dose	 250 mg	 180 mg	 140 mg	 100 mg	 20 mg	 5 mg	Rad Onc appt time
Date	dose	250 mg	180 mg	140 mg	100 mg	20 mg	5 mg	

Week 6

Your next blood test is due: _____

 START DATE	TEMODAL dose	 250 mg	 180 mg	 140 mg	 100 mg	 20 mg	 5 mg	Rad Onc appt time
Date	dose	250 mg	180 mg	140 mg	100 mg	20 mg	5 mg	

Taking TEMODAL alone

TEMODAL only

Day 1

T	T	T	T	T		

No TEMODAL for 23 days

Day 28

This monthly cycle may be undertaken up to 6 times

UP TO 6 MONTHS

Ongoing monitoring and individualised treatment

Ask your doctor to fill these details out for you.

You will take TEMODAL for _____ cycles (1 cycle = 28 days [the first 5 days you take TEMODAL then the next 23 days no TEMODAL is taken]).

(Note: your dose may change over this period.)

Daily instructions








For the first 5 days of the cycle take TEMODAL first thing in the morning or evening on an empty stomach, as directed by your healthcare professional.

Please follow these steps:

Step 1	Take _____ to prevent nausea & vomiting.	
Step 2	Wait 30–60 min	30–60 min
Step 3	Take TEMODAL capsules on an empty stomach, with water. Swallow capsules whole. Do not open or chew.	
Step 4	Wait one hour before having any food or taking medication.	60 min








Cycle 1

Your next blood test is due: _____

 Date	TEMODAL dose	 250 mg	 180 mg	 140 mg	 100 mg	 20 mg	 5 mg
<i>NO TEMODAL FOR 23 DAYS</i>							








Cycle 2

Your next blood test is due: _____

 Date	TEMODAL dose	 250 mg	 180 mg	 140 mg	 100 mg	 20 mg	 5 mg
<i>NO TEMODAL FOR 23 DAYS</i>							








Cycle 3

Your next blood test is due: _____

 Date	TEMODAL dose	 250 mg	 180 mg	 140 mg	 100 mg	 20 mg	 5 mg
<i>NO TEMODAL FOR 23 DAYS</i>							








Cycle 4

Your next blood test is due: _____

 Date	TEMODAL dose	 250 mg	 180 mg	 140 mg	 100 mg	 20 mg	 5 mg
<i>NO TEMODAL FOR 23 DAYS</i>							








Cycle 5

Your next blood test is due: _____

 START DATE	TEMODAL dose						
Date	TEMODAL dose	250 mg	180 mg	140 mg	100 mg	20 mg	5 mg
<i>NO TEMODAL FOR 23 DAYS</i>							

Cycle 6

Your next blood test is due: _____

 START DATE	TEMODAL dose						
Date	TEMODAL dose	250 mg	180 mg	140 mg	100 mg	20 mg	5 mg
<i>NO TEMODAL FOR 23 DAYS</i>							

Your additional medication summary *(tick where appropriate):*

In addition to your TEMODAL chemotherapy, you have been prescribed:

_____, to prevent nausea and vomiting.

Take it 30–60 min prior to taking TEMODAL.

_____, to prevent opportunistic infections.

To be taken at a dose of _____, on the following days:

_____, _____, _____.

_____, to reduce swelling and pressure.

To be taken as directed.

The current dose is: Stable Increasing Tapering

_____, to prevent seizures from occurring due to the tumour.

Take it as directed _____.

_____, for constipation.

Take it as directed _____.

_____.

Take it as directed _____.

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Level 1 – Building A, 26 Talavera Road,
Macquarie Park NSW 2113.
ONCO-1198047-0000.
Date of preparation July 2017.