

Adult gliomas

(astrocytomas and oligodendrogliomas):
a guide for patients, their families and carers

April 2011

ISBN: 978-0-9807421-3-8

This work is copyright. Apart from any use as permitted under the Copyright Act 1968, no part may be reproduced by any process without prior written permission from the Cancer Council Australia.

Requests and enquiries concerning reproduction and rights should be addressed to the Copyright Officer, Cancer Council Australia, GPO Box 4708, Sydney NSW 2001, Australia.

Website: www.cancer.org.au. Email: info@cancer.org.au.

Disclaimer

The information in this guide is not intended to take the place of medical advice. Information on brain tumours is constantly being updated. A patient's general practitioner or specialist may provide them with new or different information which is more appropriate to their needs.

Where to obtain copies

This guide can be downloaded from the Cancer Council Australia website
www.cancer.org.au/clinicalguidelines

Copies of this guide can be ordered through:

Cancer Councils in each state (Cancer Helpline): 13 11 20

Related Documents

Clinical practice guidelines for the management of adult gliomas: astrocytomas and oligodendrogliomas, website www.cancer.org.au/clinicalguidelines

Suggested citation

Cancer Council Australia. Adult gliomas (astrocytomas and oligodendrogliomas): a guide for patients, their families and carers. Sydney: Cancer Council Australia / Clinical Oncological Society of Australia; 2011.

Foreword

Brain tumours are uncommon, but they can have a devastating effect on patients' lives and the lives of their families and carers. This guideline has been developed to provide information about malignant brain tumours (specifically gliomas) in adults, for people with cancer and their families and carers.

This booklet has been designed as a summary of current Australian guidelines for doctors: the *Clinical practice guidelines for the management of adult gliomas: astrocytomas and oligodendrogliomas*, published in 2009 by the Australian Cancer Network/Cancer Council Australia. There are many other helpful information booklets and other resources about brain tumours available from www.cancercouncil.com.au or Cancer Council Helpline 13 11 20.

Over the past decade there has been considerable improvement in outcomes for patients with glioma. There has been a growing interest in research to increase survival and improve patients' experience. There is now high-quality evidence from many clinical trials of brain tumour treatments and supportive care. These guidelines bring together a wide range of evidence to give an overall picture of the current state of the art in brain tumour management.

This guideline covers all aspects of patient care, not just treatment targeting the tumour itself. It includes information about symptoms, diagnosis and brain scans, and separate sections on treatment for low-grade astrocytoma, high-grade astrocytoma and oligodendrogliomas.

The guideline also provides information on topics that are of particular interest for some patients, including:

- participation in clinical trials
- what is currently known about the effectiveness of complementary, alternative and unproven treatments
- psychological and social support
- managing symptoms
- driving vehicles
- rehabilitation
- follow-up
- palliative care options.

As with all of the Australian guidelines produced by the Clinical Guidelines Network, Cancer Council Australia, these guidelines were produced by a group of experts who have donated their time and have spent many laborious hours reviewing the medical literature and conferring with their colleagues.

We are especially grateful to Ms Christine Vuletich at Cancer Council Australia for her unstinting efforts to manage and produce the finished guidelines document. The adult glioma guidelines have benefited greatly from the guidance, wisdom, persistence and energy of Emeritus Professor Tom Reeve who has steered the executive group through the very long process of guidelines development.

The clinical guidelines on which this summary is based would not have been possible without the generous donation of Mr Steven Newton in memory of his wife, Valerie.

Professor Michael Barton OAM

Chair, Brain Tumour Guidelines Working Party

Professor of Radiation Oncology, UNSW

Denis Strangman

Consumer Representative, Working Party to develop Clinical Practice Guidelines for the Management of Astrocytoma and Oligodendroglioma in Adults

Chair and Co-Director, International Brain Tumour Alliance

Secretary, Brain Tumour Alliance Australia Inc

Contents

About this information booklet	7
1. Basic facts about brain tumours.....	8
Background	8
How common are brain tumours?.....	9
Types of brain tumours	10
What causes brain tumours?.....	11
Survival with a brain tumour	12
Can screening programs identify brain tumours before they cause problems?	12
2. Getting the most out of the health system.....	13
Getting help when problems arise	13
Dealing with medical staff	14
Getting the right information	15
Counselling.....	16
Making decisions about treatment.....	17
Coping with difficult medical procedures and treatment.....	18
3. Participating in brain tumour research.....	20
Why clinical trials are important.....	20
The purpose of different types of clinical trials	20
Clinical trials in Australia	22
Participating in a clinical trial	23
4. Symptoms of brain tumours.....	25
Symptoms at the time of diagnosis.....	25
Headache	26
Problems with thinking (cognitive function).....	27
Seizures.....	28
Other symptoms caused by nerve damage.....	28
5. Imaging (brain scans)	29
Reasons for doing a brain scan	29
Types of brain scans.....	30
Brain scans after treatment for a brain tumour.....	32
Limits of brain scans.....	32
6. Pathology and diagnosis	33
Why it is important to take a specimen	33
What happens in the pathology laboratory	33
7. Low-grade astrocytomas	37
Background facts	37

How doctors diagnose a low-grade astrocytoma.....	38
Treatment for people with low-grade astrocytomas	39
8. High-grade astrocytomas	44
Background facts	45
How doctors diagnose a high-grade astrocytoma.....	45
Prognosis.....	47
Before starting treatment.....	48
Initial treatment for people with high-grade astrocytomas	48
Managing high-grade astrocytomas that recur after initial treatment.....	53
9. Oligodendrogliomas.....	56
Background facts	57
How doctors diagnose an oligodendroglioma	57
Prognosis.....	59
Before starting treatment.....	60
Treatment for low-grade oligodendrogliomas or oligoastrocytoma	60
Treatment for high-grade oligodendrogliomas or oligoastrocytoma.....	63
Follow-up	64
Managing oligodendrogliomas that recur after initial treatment.....	64
10. Complementary, alternative and unproven therapies.....	67
Background	67
Possible benefits of complementary and alternative medicine.....	68
Possible unwanted effects	70
11. Managing symptoms and complications	72
Seizures.....	73
Skin problems	77
Blood clots (venous thromboembolism)	79
Swelling in the brain (oedema).....	80
Other side effects of cancer treatments	81
12. Psychological and social issues for people with brain tumours.....	84
Background	86
Distressing physical problems	86
Changes in personality	86
Problems with thinking (cognitive impairment).....	87
Anxiety, depression and other problems with mental health	88
Getting reliable information and planning for the future	89
Quality of life concerns.....	90
Treatments that help people cope	90

13. Rehabilitation	92
Background	92
Aims of rehabilitation	92
Driving	93
14. Follow-up	94
Why, when and how often?	94
Who should provide follow-up?	94
Adjusting medicines	95
15. Palliative care.....	96
Background	96
What is palliative care?	97
Organising palliative care	97
When should palliative care start?	98
Managing symptoms	100
Managing special problems at the end of life	101
Care of the dying patient.....	103
Bereavement and support of families.....	105
Appendix 1. Working party membership and reviewers	106
Brain tumour consumer guide working party	106
Reviewers	106
Acknowledgements	107
Appendix 2	108
Glossary.....	108
Abbreviations	110
Index.....	111

About this information booklet

Purpose

This booklet is intended for patients, their families and carers, and anyone interested in finding reliable information about the medical care of adults with gliomas, which are the most common types of malignant brain tumours.

The information in this booklet is a summary of the Cancer Council Australia's guidelines for doctors on the best care and treatment for adults with gliomas (*Clinical practice guidelines for the management of adult gliomas: astrocytomas and oligodendrogliomas*. August 2009), referred to as 'glioma management guidelines for doctors' in this booklet.¹ This booklet contains a shorter and simpler version of the key points, recommendations, and information that are in the glioma management guidelines for doctors.

For readers who need more detailed clinical information, the full glioma management guidelines are available from the Cancer Council Australia website (www.cancer.org.au/clinicalguidelines) or by contacting Cancer Council Australia (email info@cancer.org.au or phone 02 8063 4141).

Types of tumours included in this information booklet

This booklet includes information about gliomas, which include several types:

- astrocytoma
- glioblastoma multiforme (GBM)
- oligodendroglioma
- oligoastrocytoma.

This booklet does *not* include information about these types of tumours:

- meningiomas – benign tumours that grow from the membranes surrounding the brain and spinal cord
- pituitary tumours – benign tumours in the pituitary gland
- secondary (metastatic) cancers – cancers that began somewhere else in the body but have spread to the brain.

¹ Australian Cancer Network Adult Brain Tumour Guidelines Working Party. *Clinical practice guidelines for the management of adult gliomas: astrocytomas and oligodendrogliomas*. Sydney; Cancer Council Australia, Australian Cancer Network and Clinical Oncological Society of Australia Inc: 2009.

1. Basic facts about brain tumours

Key points

- Brain tumours are rare.
- Brain tumours can be benign or malignant.
- Astrocytomas and oligodendrogliomas are the most common types of malignant brain tumours.
- We do not know what causes most brain tumours. They occur randomly.
- Most people with a primary malignant brain tumour are middle-aged adults at the time of diagnosis.
- Over the last 20 years, there has been an increase in the number of new cases of malignant brain tumours diagnosed each year.
- Survival after treatment for a brain tumour varies between patients and depends on where the tumour is, the type of tumour and its grade, and the person's age and general health.
- There is no screening test to find brain tumours early in healthy people.

Background

In this booklet, “tumour” refers to an abnormal growth (Table 1.1). Brain tumours can be benign (slow-growing and remaining in the part of the body where they began) or malignant (rapid-growing, capable of spreading to other body parts, and life-threatening).

Table 1.1 Special terms used in this information booklet

Astrocytoma	A type of tumour that grows from glial cells, which normally provide structure in the brain and spinal cord
Benign tumour	A tumour that grows in one place and will not spread to other body parts. Benign tumours can be dangerous if they take up too much space inside the skull.
Cancer	A malignant tumour, or the disease caused by a malignant tumour
Central nervous system	The brain and spinal cord
Glioblastoma multiforme (GBM)	A high-grade (more rapidly growing) type of astrocytoma. (The terms “glioblastoma multiforme”, “glioblastoma” and “grade IV astrocytoma” all refer to the same disease.)
Gliomas	The group of brain tumours that includes astrocytomas and oligodendrogliomas
Grade	The grade of a tumour is identified by the pathologist examining the specimen according to an internationally accepted system, and is reported as a

	number. The grade of the tumour gives an indication of whether it is likely to grow slowly or quickly.
Tumour	A growth or ‘lump’ made of cells that have begun to grow in an unusual way. Tumours may be benign or malignant.
Malignant tumour	A tumour that grows in an uncontrollable way, invading organs and spreading to other body parts through the blood
Primary tumour	A tumour that has begun growing in a particular organ (e.g. brain), rather than having spread to that organ from another place. ‘Brain tumour’ means primary tumour of the brain.
Oligodendroglioma	A type of tumour that is thought to grow from oligodendrocytes, which are cells that normally provide insulation to nerves in the brain
Secondary (metastatic) cancer	A cancer that began growing in one part of the body but has spread to begin growing a new tumour in a different organ (e.g. the brain)

How common are brain tumours?

Primary malignant tumours of the central nervous system (brain and spinal cord) are rare. Only 7 people out of every 100,000 people in Australia (total of 1,472 people) were diagnosed with primary malignant brain tumour in 2007, the latest year for which national figures are available. In comparison, nearly ten times more people were diagnosed with bowel cancer in the same year (63 people out of every 100,000 people in Australia).

The number of new cases diagnosed each year (incidence) has increased slightly over the last 20 years. However, this does not necessarily mean that more brain tumours are actually occurring. The increase may be because more brain tumours are being discovered with improved scanning techniques and because doctors are performing scans in more elderly patients than in the past.

The introduction of scanning with computed tomography (CT) in the late 1970s and magnetic resonance imaging (MRI) in the mid-1980s has made it easier to find brain tumours. In particular, low-grade astrocytomas are more easily visible with MRI than with CT.

Most people with a primary malignant brain tumour are middle-aged adults at the time of diagnosis. The median age at diagnosis of malignant brain tumours in Australia was 55–59 years for men and 60–64 for women in 1999.¹¹ Gliomas are slightly more common in men than in women.

The incidence of gliomas does not vary much between geographical regions within Australia.

¹¹The median is the midpoint between the youngest and oldest age-group at diagnosis, when all patients’ ages are listed in order. This means that about half of Australians diagnosed with a brain tumour are older than the median age-group.

Types of brain tumours

Gliomas (astrocytomas and oligodendrogliomas) are the most common types of malignant brain tumours. Together, they make up about 40% of all primary brain tumours and around 70% of all primary malignant brain tumours.

Most astrocytomas and oligodendrogliomas occur in the brain. Only 5% occur in the spinal cord.

Astrocytomas

Astrocytomas grow from glial cells. Glial cells provide structure in the brain and spinal cord, and probably have other functions such as nourishing nerve cells and playing a role in learning and memory.

Astrocytomas can occur in any part of the brain or spinal cord. They can either grow slowly, or grow rapidly and invade surrounding brain tissue. Astrocytomas are classified by grade from one to four (I–IV) based on how much they look like normal brain tissue. A higher grade means that the tumour is less like normal brain cells and grows faster.

Grade I astrocytomas are also called pilocytic astrocytomas. These tumours occur in children and young adults. They are less invasive than other grades and have a relatively good prognosis. (Pilocytic astrocytomas are not discussed further in this information booklet).

Grade III astrocytomas are also called anaplastic astrocytomas. Grade IV astrocytomas are often called glioblastoma multiforme (GBM).

A low-grade (grade II) astrocytoma can change over time to become a high-grade (grade III or IV) tumour. Some gliomas begin as grade IV tumours.

The incidence of astrocytomas seems to be falling each year, but this may be because the criteria for determining whether a brain tumour is an astrocytoma or an oligodendroglioma have changed.

Oligodendrogliomas

Oligodendrogliomas probably grow from oligodendrocytes, which are cells that insulate nerve fibres in the brain.

People with this type of tumour may survive longer than people with astrocytomas.

Some gliomas can contain both oligodendroglioma and astrocytoma. This type of tumour is called “mixed oligoastrocytoma”.

Oligodendroglioma are classified as:

- grade II – low grade
- grade III – high grade, also called anaplastic oligodendroglioma.

Oligodendrogliomas are often located near the surface of the brain. People with oligodendrogliomas may have had seizures for a long period of time before the tumour is diagnosed.

The incidence of oligodendroglioma (the number diagnosed each year) has risen recently, but this is probably because the criteria for determining whether a brain tumour is an astrocytoma or an oligodendroglioma have changed.

What causes brain tumours?

The causes of brain tumours are not well known and they appear to occur randomly. For the vast majority of people with a brain tumour, no outside cause can be clearly identified.

Most astrocytomas and oligodendrogliomas occur when there is damage (a mutation) in genes that control how a cell grows and multiplies. The cells with the gene mutation develop into the tumour, but the abnormality cannot be inherited by the person's children.

Known risk factors for astrocytomas and oligodendrogliomas include:

- ionising radiation (X rays and gamma rays)
- ageing
- male sex (slightly higher risk than for females)
- genetically inherited tendency (rare).

Radiation

Exposure to ionising radiation (such as X rays and gamma rays) can cause brain tumours, but cases where this is the known cause are very rare.

Non-ionising electromagnetic radiation (such as radio waves, microwaves, ultraviolet rays or infrared rays) has been suspected as a cause of malignant brain tumours for many years, but there is not strong evidence that this is an important cause. Studies in people exposed to high levels of non-ionising electromagnetic radiation, such as electrical workers and heavy users of mobile phones, have mainly shown no effect. For earlier-generation analogue-type mobile phones, prolonged use has been associated with a slight increase in the incidence of benign brain tumours.

Studies conducted more recently do not provide clear evidence for whether or not non-ionising radiation increases the risk of brain tumours.

Genetically inherited tendency

People with certain rare genetic conditions have a higher risk of developing a brain tumour than the general population. These include people with:

- neurofibromatosis type 1
- neurofibromatosis type 2
- Li-Fraumeni syndrome
- Turcot syndrome.

People from families that seem to have more brain tumours than average should be referred to a cancer genetics service, which is a special clinic for people with familial (inherited) cancers.

Why we don't know the causes of brain tumours

Brain tumours are rare, so it is extremely difficult to collect information about a large enough group of cases to enable statisticians to make reliable conclusions.

However, information is being collected around the world, and researchers plan to analyse data from a large number of patients with gliomas. Research is underway into whether certain genes are important risk factors for brain tumours.

Survival with a brain tumour

Survival time after treatment for a brain tumour varies and depends on several factors, including:

- the type of tumour
- the location of the tumour within the brain
- the tumour grade
- how much tumour was removed during surgery
- the person's age
- the person's general health.

It is difficult to predict accurately the outcome for a person with a brain tumour. The survival times listed here are averages. Because each person's circumstances are different, they may not give an accurate idea of survival time that can be expected for an individual. Current average survival times are approximately:

- up to 10 years for people with low-grade oligodendroglioma
- five to eight years for people with low-grade astrocytoma
- three years for people with anaplastic astrocytoma
- one to seven years for people with anaplastic oligodendroglioma
- one to two years for people with GBM (grade IV astrocytoma).

Although these average survival times may seem confronting, it is important to remember that many patients survive much longer than the averages listed here.

Can screening programs identify brain tumours before they cause problems?

No, screening for brain tumours in healthy people with no symptoms is not feasible.

Screening is most effective for cancers that are common, can be detected early using a specific, safe, reliable and cost-effective test, and can be treated effectively if detected early. Unlike cervical cancer, breast cancer or bowel cancer, malignant brain tumours are not suitable for screening programs. There is no known cost-effective test and early detection of malignant brain tumours does not significantly improve the benefit of treatment.

2. Getting the most out of the health system

Key points

- People with a diagnosis of a brain tumour, and their families or carers, face special emotional, physical and practical challenges.
- Patients and their families or carers should talk to their healthcare team about any problem they are facing, so that help can be arranged.
- The best care for a person with a brain tumour involves doctors and other health professionals, with a range of different areas of expertise, working together as a team (this is called multidisciplinary care). Patients and their families should make sure they know which person to contact first when they have any concerns.
- Patients have the right to ask for a ‘second opinion’ – having a different doctor assess their tumour and prognosis, and give advice about treatment options.
- Patients and their families or carers have the right to receive information they can understand, to ask questions, and to check the information when it is not clear. Doctors and other health professionals should encourage people to ask questions about any of the information that they don’t understand.
- A person with a brain tumour should be encouraged to bring a friend or family member to medical consultations, if they wish. Having someone else there can help them remember the information and feel supported.
- Talking about feelings is generally helpful for people with brain tumours.
- Trained counsellors are available for more support, if needed. Patients and their families should ask their doctors about available counselling services.
- Generally, doctors should encourage people with any medical condition to be involved in making treatment decisions. However, making decisions can be especially difficult for people with brain tumours who have problems with thinking, understanding and reasoning because of the tumour or medicines.
- Early after the diagnosis, a person with a brain tumour should consider asking someone else to take responsibility for making decisions for them in future, if they cannot make decisions for themselves.

Getting help when problems arise

Medical problems

As well as problems caused by the tumour, people with brain tumours may experience difficulties due to side effects of treatments. Corticosteroid treatment, such as dexamethasone, can change a person’s physical appearance, disturb their sleep, affect their mood, weaken muscles and change blood glucose (sugar) levels.

People with brain tumours will usually need other treatments including anticonvulsant medicines, oral chemotherapy, medicines to stop vomiting or constipation, antibiotics, and

medicines to prevent blood clots. All of these can cause side effects and can interact with medicines that the person is already taking for other medical conditions.

Patients and their carers should tell their doctors if any of these problems occur, so that they can be dealt with. (There is more information about problems caused by the tumour or treatments in **Chapter 12. Psychological and social issues for people with brain tumours.**)

Practical problems for carers

Family members and carers of patients with brain tumours also face practical challenges including coordinating the patient's care, organising travel for specialist treatment, and taking on new roles such as caring for young children or organising adjustments in the home (e.g. to allow for wheelchair access). It is even more difficult to cope if the diagnosis means financial hardship because the patient, carer or both are unable to continue paid work.

Patients and their families or carers should talk to their healthcare team about any practical problems they are having and ask for access to services that can help. Most health services can arrange for an assessment by trained experts such as social workers, who can help people access healthcare, social and financial services for which they are eligible, such as Centrelink payments (e.g. Disability Support Pension, Carer Allowance or Carer Payment) or early access to superannuation.

Dealing with medical staff

Working with a large care team

The best care for a person with a brain tumour involves doctors and other health professionals, with a range of different areas of expertise, working together as a team to provide assessment, treatment and follow-up. Team members may include a neurosurgeon, radiation oncologist, medical oncologist, neurologist, endocrinologist, rehabilitation physician, palliative care physician, clinical care coordinator, social worker, psychologist or psychiatrist, occupational therapist, physiotherapist, community nurse, dietitian, registrars and nurses.

This means that patients and their families or carers will probably be dealing with many different staff members, so it is important to know who to contact first about any day-to-day concerns.

Many people find it daunting at first to cope with seeing a large number of health professionals. It may be helpful to keep a list of everyone in the treatment team. Patients and their families shouldn't feel embarrassed about asking who each person is and what their role is in the team, and should ask all team members to include the person's general practitioner in any letters and reports.

Some treatment centres have a brain tumour care coordinator who can assist the patient and family.

Getting a second medical opinion

At any time in their treatment, patients have the right to ask a different doctor to give an opinion about their prognosis or treatment. Getting a second opinion may help clarify answers

to questions and help the person decide which treatment they would prefer and which doctor they would prefer to manage their tumour.

When the advice from different doctors is the same, this can help the person feel confident that the information is accurate and that they are being given the best possible care.

Patients should not feel embarrassed or anxious about asking their doctor to provide referral for a second opinion. This is an accepted part of medical practice.

If patients or their family would like a second opinion, it is often more beneficial to get this opinion before starting treatment.

Getting the right information

Information about the diagnosis

Anyone facing a serious diagnosis wants to know their situation as soon as possible. Several tests must be done before an accurate diagnosis can be given, and these may take a week or more to complete after surgery.

While waiting, it can be stressful for patients and their families and carers to cope with uncertainty, but is important for doctors to make sure the information is as accurate as possible before explaining the diagnosis.

Information given during consultations

It can be difficult for anyone to remember all the information received during a visit to a medical specialist. Even when a person is expecting to hear bad news, the diagnosis or information about the chances of survival may be a shock. People in these circumstances often find that they ‘switch off’ and don’t remember a lot of what they have been told. It can be helpful to arrange for someone else (e.g. a friend or family member) to be present during medical consultations, especially when getting results.

Patients should let their doctors know how much information they would prefer at each session. Some people will want their doctor to tell them everything immediately, even if the news is bad (see *Discussing the outlook (prognosis)* later in this chapter). Others will prefer to hear an outline at first, then think about things before asking for more information. Some patients might want to ask about possible participation in any relevant clinical trials.

Patients and their families or carers have the right to receive information they can understand. They should feel free to ask questions, to check the information when it is not clear, and to ask doctors to repeat anything they missed. Patients should ask their doctor to write down the most important information, and should feel free to ask about what other kinds of information are available (e.g. printed information, CDs or DVDs).

People with cultural issues they would like to discuss with a trained professional should ask their doctor to arrange this. People whose first language is not English should ask their doctor to arrange for a health interpreter to come to consultations. It is better to use a trained professional health interpreter than to rely on family members to interpret. Usually a family member or carer cannot be a good interpreter and support the patient properly at the same time. There is less stress and the information is clearer with a professional interpreter, who is trained in how to translate medical terminology and how to deal with people who have cancer.

Telling other people about the diagnosis

If patients feel that the news about their diagnosis will be difficult to explain to other people, such as young children, they should ask their doctors for help with this issue.

More information

A booklet about telling children about the diagnosis (*Talking to kids about cancer. A guide for people with cancer, their families and friends*), is available from www.cancercouncil.com.au or Cancer Council Helpline 13 11 20

Discussing the outlook (prognosis)

When the prognosis for a person with a brain tumour is not good, it is distressing for them and their family. However, many people in this situation say that being told the worst possible outcome allows them to think about the future, make plans, and make sure that their family members understand the situation.

Not everyone feels like this and some will prefer not to be told the worst possible scenario. People with cancer should let their doctor know how they want to handle information about the prognosis.

Often a person finds it easier to understand information about the outlook if their doctors explains it in several different ways – for example, tells them the average survival time for a person with the particular type of tumour and the longest survival times using words, statistics and graphs. If a patient, their family or carer finds it hard to understand the information, they should ask the doctor to explain it in a different way.

How a person feels about their need for information may change over time. At any time during treatment, they can tell someone in the treatment team if they would like information about the prognosis.

Counselling

Most people with brain tumours find it helpful to talk about the information they have been given. Sometimes it can be useful to talk with a specially trained counsellor such as a psychologist, social worker or psychiatrist.

Often, patients prefer to talk to a trained professional about their anxieties and fears instead of talking to their family.

The doctor or the person coordinating multidisciplinary care will be able to arrange counselling or explain about the services that are available.

Making decisions about treatment

Doctors' responsibilities

In Australia, doctors have a clear responsibility to ensure that patients receive the information they need to make decisions about treatment.ⁱⁱⁱ The information must be in a form that patients and their families can understand and which is appropriate to their cultural background and personal values. Generally, doctors should encourage people with any medical condition to be involved in making treatment decisions. The doctor's role is to give the patient honest information and advice and help them to come to a decision, but not force a decision on them.

Making decisions can be difficult for someone while they are still adjusting to the stress of receiving a diagnosis of a serious illness. It may be hard to concentrate, to process all the information, and to work out the likely risks and benefits of each treatment option. Making decisions about treatment can also force the person to face difficult thoughts about their goals, personal values, social, occupational and family roles.

For people with brain tumours, making decisions can be especially difficult because of problems with memory, processing information, planning and reasoning, which are caused by the tumour or treatments. Sometimes the person has difficulty expressing their thoughts and wishes. All these problems can make it very hard to make a decision about treatment and communicate it to others.

Despite these challenges, doctors should make sure that patients have the opportunity to participate in making decisions about their treatment as much as they are able. (There is more information about decision-making in **Chapter 12. Psychological and social issues for people with brain tumours.**)

Sometimes there is an opportunity for a person with a brain tumour to participate in research by agreeing to tests or being in a clinical trial of a treatment. There are national ethical and legal guidelines that doctors must follow when giving the person information about the research and getting their consent to participate. (There is more information about giving consent to participate in a clinical trial in **Chapter 3. Clinical trials and research.**)

Asking another person to make decisions for the patient

Even when a person with a brain tumour feels mentally well at the time of the diagnosis, they may later develop problems with thinking and decision-making. Most people find it painful to think about the possibility that they may not be able to make independent decisions in the future. However, it is generally helpful for the person and their family to think about this early and make a contingency plan, just in case the person's health worsens in future.

Early after the diagnosis, a person with a brain tumour should consider asking someone to take responsibility for making decisions for them in future if they cannot make decisions for themselves. This can help the patient, their family and health professionals feel more confident about future decision-making. A social worker or another member of the patient's care team can provide information about how to appoint a 'surrogate decision maker' in your state or territory. (There is more information about decision-making in **Chapter 12.**)

ⁱⁱⁱ Doctors' responsibilities for providing information are set out in guidelines produced by the National Health and Medical Research Council (National Health and Medical Research Council. General guidelines for medical practitioners on providing information to patients. Canberra: Commonwealth of Australia; 2004).

Psychological and social issues for people with brain tumours and Chapter 15. Palliative care.)

If a patient nominates someone (usually a close family member) to be a surrogate decision maker, they should tell the person about which treatment they would prefer in different situations. Making their wishes known will enable the nominated decision maker to express the person's wishes on their behalf. This type of planning can give the patient confidence that they will continue to be treated according to their wishes, even if they can no longer express these. It also reduces distress for family members and health professionals, because they can feel confident that they are continuing to respect the patient's wishes.

Coping with difficult medical procedures and treatment

A person with a brain tumour will usually undergo several medical procedures during the processes of diagnosis, treatment and follow-up.

Even tests that do not normally cause pain or physical discomfort, such as blood tests and X-rays, can be highly stressful for the person if they are anxious about the meaning of the test results. Other procedures, such as surgery, radiotherapy and chemotherapy can be uncomfortable or painful, have significant side effects, or may not be available nearby, so the person needs to spend time away from home and away from their normal sources of emotional support.

When undergoing any test or procedure, the patient and their family or carers should make sure they fully understand what it is for, what it involves and what to expect during and after (Table 2.1). There is good evidence that people who have this information generally find tests and procedures less stressful, and may experience fewer and less severe side effects. For example:

- The noise of a magnetic resonance imaging (MRI) machine can be quite alarming if a person is not prepared for this, but most people can cope if they know that the test will not take long.
- Coping techniques, such as deep breathing or distraction technique, can help people undergoing some procedures.
- Medicines to prevent or control nausea can make people more comfortable during chemotherapy.
- People may feel confused or anxious when waking up after surgery, but it helps to know they will be closely monitored and looked after by experienced staff, and that medicines are available to control physical problems, if necessary.

Patients should never feel embarrassed about asking 'dumb' questions.

Table 2.1 Information checklist for tests and procedures

What is the procedure for?

- If taking a blood sample, which tests will be done and what will the results mean?

Where will the procedure take place?

- Does the patient have to be there at a particular time?
- Are there any special requirements (such as fasting before the test, what to wear)?

Who will do the procedure?

- Exactly what does the procedure involve?
- How long it will last?
- What is the patient likely to experience?
- Will there be discomfort or pain?

What might help the person cope with the procedure?

- Are there any techniques that people find helpful?
- Is there anything that can help make the procedure more comfortable (such as medicines)?

What is the person likely to experience after the procedure?

- What do most people experience afterwards?
- Who will look after the person?
- What kind of help is there if problems occur or if the person experiences pain or discomfort?

Adapted from *Clinical practice guidelines for the psychosocial care of adults with cancer*^{iv}

^{iv} National Breast Cancer Centre, National Cancer Control Initiative. *Clinical practice guidelines for the psychosocial care of adults with cancer*. Camperdown, NSW: National Breast Cancer Centre; 2003.

3. Participating in brain tumour research

Key points

- Clinical trials are important for the future of good medical care. Most advances in the treatment of brain tumours have happened because new approaches were tested in clinical trials.
- Testing a new treatment involves four phases of clinical trials over time. Each phase has a different aim.
- In a randomised clinical trial, participants are randomly selected to receive the new treatment, while the other group receives standard treatment. When agreeing to participate in the clinical trial, each patient does not know whether they will be given the new treatment or the standard treatment. This is necessary to reduce the risk of a biased result.
- Clinical trials in Australia may be run by pharmaceutical companies, cooperative research groups (groups of doctors and researchers), or hospitals.
- All clinical trials must be approved by a Human Research Ethics Committee before patients can be invited to participate. The committee carefully assesses the design and any possible problems for patients before deciding whether the trial is safe, ethical and appropriate for patients.
- People with brain tumours can still participate in clinical trials even if they have cognitive impairment (problems with memory, thinking, reasoning, understanding information, making decisions or judging their actions) or problems with writing and speech.

Why clinical trials are important

Just because a treatment is new does not mean it is better. Some new treatments may even be harmful. Clinical trials are the main way of finding out if a new treatment is better than the current best treatment of cancers, including the treatment of brain tumours.

Clinical trials are important because only proper, rigorous scientific testing can enable researchers to discover whether or not a new treatment (such as a medicine, surgical technique or type of radiotherapy) is better than the best available standard treatment. If a treatment has not been tested properly in clinical trials, it remains unproven and can be controversial.

Clinical trials give patients the opportunity to receive new treatments and to make a contribution to the improvement in the care of future patients.

Recent advances in brain tumour treatments have been made after researchers analysed the results of large, well designed and well conducted clinical trials. These trials have led to new treatments for brain tumours, which are now approved by the Australian Therapeutic Goods Administration and paid for by the Pharmaceutical Benefits Scheme.

The purpose of different types of clinical trials

Clinical trials in patients are usually performed after years of scientific testing in the laboratory and in animals. Any treatment that seems to be effective must then be tested in

patients to find how it should be given, how safe it is, what the side effects are and whether it is effective in people with the condition.

Clinical trials are conducted over time at different stages to collect different types of information about the new cancer treatment. There are four phases numbered one to four (I–IV).

Phase I trials

Phase I trials are the first studies in patients. They aim to find out how the treatment should be given, how often it should be given, and what dose is safe. Treatments used in Phase I trials rarely cause a tumour response.

Phase II trials

Phase II trials continue to test the safety and side effects of the new treatment, and also evaluate how effective it is in treating patients with a particular disease.

Phase III trials

Phase III trials test the new treatment by comparing it with an accepted standard treatment to find differences in effectiveness against the disease, safety and side effects.

These trials are randomised, which means patients are randomly selected to either get the new treatment or get the standard current treatment. Neither patients nor the doctors can choose which group a person will be in. This way of designing a trial ensures that patients in each group are similar overall.

Phase III trials can also be ‘blinded’, which means they are designed so that patients and doctors do not know which treatment the patient is receiving. This method makes the results more reliable, because it helps prevent patients’ and doctors’ expectations affecting their experience of receiving the treatment or observing its effects. However, sometimes a trial may not be blinded when it is not possible to disguise treatments. Cancer trials are not usually blinded.

Sometimes there is no accepted standard treatment that the new treatment can be compared with. In this situation a groups of patients taking the new treatment is usually compared with a similar group receiving usual care, or with a group receiving placebo.

Phase III trials provide the most reliable type of evidence. They are usually required by health system authorities before a new treatment can become a standard part of care.

Phase IV trials

Phase IV trials are usually run after a new treatment has already been proved effective in earlier trials, and has been approved by government for use in patients. These trials collect more information about long-term safety or side effects. Patients do not have to pay for the treatment in a clinical trial, so Phase IV trials also provide a way for patients to receive the new treatment even if it is not yet widely available or is too expensive (for example, when it is not subsidised by the Australian Government through the Pharmaceutical Benefits Scheme).

Clinical trials in Australia

Who conducts clinical trials?

In Australia, clinical trials in patients with brain tumours may be conducted by:

- **Pharmaceutical companies.** Pharmaceutical companies that develop new medicines must complete phase I, II and III trials before they are permitted to market their product. Many clinical trials of new treatments for brain tumours are sponsored by pharmaceutical companies. These trials usually have a sound scientific basis and are well designed and conducted. All doctors involved in designing and running the trial (investigators) must declare their relationship to pharmaceutical company and any fees they have received. Money received by a clinical trials unit does not go towards a doctor's salary. The money is used strictly for the conduct and management of the trial.
- **Cooperative groups.** Cooperative groups are groups of doctors and researchers who share a scientific interest in a specific disease. Cooperative oncology (cancer) groups in Australia with a special interest in brain tumours include the Trans Tasman Radiation Oncology Group (TROG) and the Cooperative Trials Group for Neuro-Oncology (COGNO). These groups are usually funded through grants from state or federal government. They may also receive funding or medicines with which to run clinical trials from pharmaceutical companies. Most clinical trials run by cooperative groups are initiated and designed by specialist doctors.
- **Individual institutions or consortia.** Sometimes a clinical trial is conducted at a few hospital units or a small group of hospitals. These are usually smaller trials such as phase I or phase II trials, studies of diagnostic tests such as scans, or studies of psychological and social issues affecting people with brain tumours.

Who approves clinical trials?

Before patients can be enrolled onto a clinical trial in Australia, the trial must be reviewed by other expert clinicians and researchers to ensure that it is scientifically well designed and will be able to answer the study question.

It must also be reviewed by at least one registered Human Research Ethics Committee to ensure that the trial protocol adheres to national guidelines as set out in the National Health and Medical Research Council's statement on ethical conduct in human research.^v

Who participates in brain tumour clinical trials?

A small proportion of people with brain tumours participate in clinical trials. In Victoria, about one in twenty (5%) patients with gliomas participate in a clinical trial during their illness, according to recent data from the Victorian Cancer Registry.

Ideally, all patients should have access to treatment in a centre where clinical trials are offered. However, geographical distances are a barrier to participation for patients in rural and remote communities. For extremely rare cancers, like anaplastic astrocytomas and oligodendrogliomas, it is unlikely that there would be enough patients in Australia alone to

^v National Health and Medical Research Council, Australian Research Council, Australian Vice-Chancellors' Committee. National statement on ethical conduct in human research. Canberra: NHMRC; 2007.

run trials, but groups like the Cooperative Trials Group for Neuro-Oncology (COGNO) sometimes participate in international trials.

Participating in a clinical trial

Understanding what the trial will involve and agreeing to participate

Doctors running a clinical trial are responsible to make sure that every person who participates:

- is given detailed information about the clinical trial, both verbally and in writing, before they agree to be involved
- understands what they are being asked to do
- agrees to be in the trial of their own will
- signs a document to show they have given their consent to take part.

This can be difficult when a person has cognitive impairment (problems with memory, thinking, reasoning, understanding information, making decisions or judging their actions).

However, the National Health and Medical Research Council's statement on ethical conduct in human research^{vi} states that people with cognitive impairment are entitled to participate in a clinical trial. That document provides guidance for their participation, and states that in some situations^{vii} consent can be given by another person who has been given legal authority to make decisions for the patient. (There is more information about appointing another person to make decisions in **Chapter 12. Psychological and social issues for people with brain tumours.**)

In some circumstances, a doctor may legally enrol a patient in a clinical trial even though the patient is unable to give their consent, if the treatment they will receive in the trial is in the patient's best interests. Patients and their families or carers should discuss these issues with the doctor.

Occasionally, a patient who is able to think clearly and wishes to participate in a clinical trial may be unable to sign the required forms due to a physical disability caused by the tumour, such as weakness of their writing hand. In this situation, alternatives depend on legislation that applies in that state or territory, for example:

- Spoken consent to participate may be legally valid if it is witnessed by an independent third party.
- Another person who is authorised under Guardianship legislation may be able to sign the consent form on the patient's behalf.

^{vi} National Health and Medical Research Council, Australian Research Council, Australian Vice-Chancellors' Committee. National statement on ethical conduct in human research. Canberra: NHMRC; 2007.

^{vii} The law governing who can give consent differs between different Australian jurisdictions. In some states, such as Western Australia, a person nominated to make decisions for a patient cannot give consent for participation in clinical trials.

What participation might involve

People participating in clinical trials may be asked to undergo extra tests or answer survey questions, and take part in follow-up tests some time after the treatment.

Participation in brain tumour clinical trials may involve being asked to:

- complete questionnaires about quality of life, which are designed to measure how the tumour and the treatment is affecting the person's wellbeing
- undergo tests to measure cognitive functioning, which can help researchers understand whether the treatment can improve thinking ability
- undergo extra blood tests to help researchers understand more about how the treatment works, who the treatment may be most effective for, how much of the treatment reaches the bloodstream, or side effects of the treatment
- give permission for the original tumour specimen (taken by biopsy or during surgery) to be sent to another place for more testing. This testing might help researchers understand more about how the treatment works or which future patients may have the most benefits from treatment.
- participate in long-term follow-up after the trial treatment stops, either in person or by phone. This allows researchers to understand the long term benefits or side effects of treatments.

4. Symptoms of brain tumours

Key points

- Symptoms that lead to the diagnosis of a brain tumour depend on several factors including the size of the tumour, its location in the brain, and how rapidly it is growing.
- After the diagnosis, family members or friends may mention other symptoms that they noticed weeks or months earlier, such as mild changes in the person's thinking or personality.
- Symptoms may include headache, nausea and vomiting, problems with thinking, memory and reasoning (cognitive impairment), seizures, or stroke-like symptoms such as weakness or blindness.
- Headache can be a symptom that alerts doctors to the possibility of a brain tumour.
- In patients with brain tumours, headaches are common. Headache can be symptoms of pressure building up inside the skull.
- Most headaches that are caused by the brain tumour itself can be treated effectively with paracetamol or nonsteroidal anti-inflammatory drugs.
- Abnormal cognitive function (problems with memory, thinking and reasoning) can be a symptom that alerts doctors to the possibility of a brain tumour.
- Treatments for brain tumours can also cause problems with cognitive function.
- Seizures can be a symptom that alerts doctors to the possibility of a brain tumour.
- If a person with a brain tumour does not have seizures at the time of diagnosis, there is only a small chance that they will develop seizures later.

Symptoms at the time of diagnosis

The most common symptoms at the time of diagnosis include headache, nausea and vomiting, cognitive impairment (problems with thinking, memory and reasoning), seizures, and stroke-like symptoms such as weakness or blindness. Patients often have more than one symptom at the time of the diagnosis.

After the diagnosis, family members or friends may mention other symptoms that they noticed weeks or months earlier, such as mild changes in the person's thinking or personality.

Symptoms of a brain tumour depend on several factors including the size of the tumour, its location in the brain, and how rapidly it is growing. For example:

- A small tumour deep within the dominant side of the brain may cause significant problems with brain function, while a tumour in the non-dominant frontal lobe may become very large before the person experiences any symptoms.
- A rapidly growing tumour, such as a glioblastoma multiforme, is more likely to cause symptoms of pressure building up inside the skull (such as headache) than a more slowly growing tumour.

- Patients with tumour in more than one area may have symptoms indicating that multiple areas of the brain are affected.

Headache

About half of all patients with brain tumours experience headache.

Headache as a clue that someone has a brain tumour

Sometimes headache is the main reason for doctors to order a magnetic resonance imaging (MRI) scan to check whether the person could have a brain tumour. An MRI scan would normally be done if a person:

- has had a history of headaches, but then the headaches change (e.g. the type of headache changes, the pattern changes, or the person also develops symptoms and signs of abnormal brain function)
- suddenly begins to experience headaches, particularly if there are also other signs of abnormal brain function.

It is unusual for headache to be the first and only symptom of a brain tumour. Usually, other symptoms have developed by the time the brain tumour is diagnosed.

In most patients, the position of the headache does not help doctors work out where the tumour is.

Pattern and type of headache

Headaches that are caused by a build-up of pressure in the skull due to swelling are typically worst early in the morning (or during the night) and disappear soon after the person gets up. They are often mild at first, but over days to weeks become gradually more severe, frequent and last longer each time, and eventually become almost constant. They are worsened by bending over and can cause nausea and vomiting.

Headaches that are due to the tumour itself, and not due to pressure from swelling, can be any type of headache. They may be exactly the same as headaches the person has experienced in the past, but usually they are more severe, more frequent, or there are also unusual symptoms. In general, they begin occurring from time to time, then get progressively worse over time. There is no typical time of day at which headaches occur. Headaches may be worse when the person bends over or changes body position, especially when getting up from bed. Up to two-thirds of people with brain tumours experience nausea and vomiting with their headache.

The most common type of headache in people with brain tumours is an ordinary tension-type headache – usually described as a dull ache, a feeling of pressure or similar to a headache caused by sinusitis. It is usually on both sides of the head, but may be worse on the side of the tumour. Some people experience migraine-like headaches, but this is less common. There may also be unusual symptoms that are not typical of migraines, including abnormal brain function. Some patients experience a mixture of headache types. Some people describe the headache as a throbbing pain or shooting pain.

Why brain tumours cause headaches

Headaches in patients with brain tumours can be due to the size of the tumour and the tumour pulling on tissues that are very sensitive to pain, such as blood vessels, brain lining (dura), and nerves that come out of the brain (cranial nerves).

Headache can also be caused by blockage in the flow of the fluid that surrounds and cushions the brain and spinal cord (cerebrospinal fluid). This can cause build-up of the fluid in the brain (hydrocephalus).

Treatment for headaches

Headaches caused by brain tumours are usually moderately severe or severe, but are only mild in about 10–20% of people. Simple pain-killers (such as paracetamol) are effective in providing moderate relief or complete relief in up to two-thirds of people with brain tumours.

Non-prescription nonsteroidal anti-inflammatory drugs such as ibuprofen (brand names include Brufen and Nurofen) can also be used. However, taking non-prescription nonsteroidal anti-inflammatory drugs at the same time as dexamethasone increases the risk of stomach upset or ulcers.

For headaches caused by swelling in the skull, dexamethasone is the main treatment because it reduces the swelling and pressure. The dose is increased until the pain is controlled, but kept as low as possible to minimise side effects. (There is more information about treatment for this type of headache in **Chapter 11. Managing symptoms and complications.**)

Problems with thinking (cognitive function)

Brain tumours can cause problems with a person's thinking (cognitive function), which includes ability to remember, learn, recognise things, solve problems, reason and make decisions.

At the time of diagnosis, a person may already have mild problems with cognitive function, especially if they have a rapidly growing, high-grade tumour. However, it is unusual for these to be the only symptoms that lead to the diagnosis of brain tumour. These symptoms do not help identify the type of brain tumour.

Problems with cognitive function in people with brain tumours are usually caused by a combination of more than one factor. These can include:

- the tumour itself or swelling around it
- epilepsy (recurring seizures) caused by tumour
- surgery
- radiotherapy
- chemotherapy
- other treatments such as epilepsy medicines and dexamethasone
- psychological distress.

In a person who has already received treatment for a brain tumour, new problems with cognitive function could indicate that the tumour is growing or becoming more invasive, or

that a new tumour has developed. Rechecking a person's cognitive function is one way of testing for this.

Dementia is very unlikely to be caused by a brain tumour.

Seizures

Sometimes seizures are the main reason for doctors to order a magnetic resonance imaging (MRI) scan to check whether the person could have a brain tumour. An MRI scan would normally be done if an adult experiences a seizure for the first time, or develops epilepsy (recurring seizures), because there is a small chance that it is due to a tumour.

Among people who have already been diagnosed with a brain tumour, about one-third experience seizures at some time. (There is information about treatment for seizures in **Chapter 11. Managing symptoms and complications.**)

Among patients who have seizures at the time of diagnosis, almost half (approximately 40%) of patients have focal seizures (seizures that affect part of the brain while the person remains conscious) and about half have generalised seizures (seizures that cause a person to lose consciousness).

It is not possible to tell exactly what type of tumour a person has from their pattern of seizures.

Only a small proportion (approximately 14%) of people with brain tumours develop seizures for the first time after being treated for the tumour. This means that if the person does not have seizures at the time of diagnosis, they are unlikely to have seizures later.

Other symptoms caused by nerve damage

People with brain tumours can develop problems caused by disruption of the nerves coming from the brain, such as weakness on one side of the face or body, problems with speech, blindness or difficulty performing everyday tasks like dressing.

These symptoms have usually been present for days, weeks, months or even years by the time the brain tumour is diagnosed. However, in some people they can happen suddenly, and could be confused with symptoms of a stroke or 'mini-stroke' (transient ischaemic attack).

When someone develops problems like these and there is a possibility that the person could have a brain tumour, an MRI scan is needed to find the cause. In some people, this is how their brain tumour is first diagnosed.

5. Imaging (brain scans)

Key points

- Brain scanning (neuroimaging) is an essential part of medical care for people with brain tumours.
- The two main types of neuroimaging used in people with brain tumours are computed tomography (CT) and magnetic resonance imaging (MRI).
- When a person has symptoms that could be caused by a brain tumour, the first scan is usually done using CT. The main aim at this stage is to see whether an abnormal area of brain is visible that could possibly be a tumour. If an abnormal growth is seen, the CT scan is normally followed up with an MRI scan.
- MRI is more accurate and generally gives more information than CT. Anyone who is about to have a brain biopsy, or surgery to remove a brain tumour, should have an MRI first.
- MRI cannot be used for people with metal inside their bodies, such as pacemakers, cochlear implants or a metal speck permanently stuck inside the eye after an accident.
- After surgery to remove a brain tumour, brain scans may be used to look for tumour that has been left behind or changes in the brain tissue caused by the surgery itself.
- MRI is the best type of brain scan for long-term follow-up after treatment for a brain tumour.
- Brain scans cannot always give reliable information about whether an abnormal area of brain is definitely a tumour, or tell the difference between types of tumours.

Reasons for doing a brain scan

All adults with astrocytomas or oligodendrogliomas will need to have brain scans (neuroimaging) during their diagnosis and treatment.

There are several reasons for doing a brain scan in a person with a brain tumour:

- to help confirm the diagnosis
- to see where the tumour is within the brain
- to assess what kind of tumour it is and how it is growing
- to assess what effects the tumour is having on the surrounding brain
- to plan biopsy, surgery or radiotherapy
- to assess whether treatment has been successful (for example, to see how much tumour has been left behind after surgery)
- to check complications caused by treatment, such as bleeding or infection in the brain
- to check whether the tumour has started growing again or has changed after treatment.

Brain scans are **not** used to look for possible brain tumours in healthy people with no symptoms (screening programs). Brain scans are used only in healthy people who are at high

risk of brain tumours, such as people with neurofibromatosis and other inherited genetic conditions.

Types of brain scans

The two main types of scans used in people with brain tumours are computed tomography (CT) and magnetic resonance imaging (MRI).

Computed tomography (CT)

CT is available in most hospitals, takes less time to do and is less expensive than MRI. CT uses X-rays (ionising radiation).

When a person has symptoms that could be caused by a brain tumour, the first scan is usually done using CT. The main aim at this stage is to see whether an abnormal area of brain is visible that could possibly be a tumour. If an abnormal growth is seen, the CT scan is normally followed up with an MRI scan (see *Magnetic resonance imaging (MRI)*, later in this chapter).

CT is also useful for:

- identifying bleeding inside the brain
- assessing whether the tumour is growing into the skull
- identifying a build-up of calcium within a tumour (calcified tissue), which can suggest that the tumour is an oligodendroglioma.

In people who cannot have MRI scans, special CT techniques can be used instead.

Magnetic resonance imaging (MRI)

MRI is significantly more expensive than CT and is not as widely available.

MRI is more accurate and generally gives more information than CT. MRI is recommended before a brain biopsy or surgery to remove a brain tumour. The most accurate type of brain scan in a person with a suspected brain tumour is MRI performed after a dye has been injected into the person's bloodstream (contrast-enhanced MRI).

CT is useful as an extra scan for assessing tumours that have grown into the bone, or for identifying calcified tissue or bleeding.

MRI uses a powerful magnet, radio waves and a computer to make images of a 'slice' in any direction through the head. The patient lies on a table, which slides inside a large metal cylinder. People who experience claustrophobia may need general anaesthesia or sedation so that they can keep still in the MRI machine during the scan.

MRI during surgery

Researchers are currently investigating whether using MRI during surgery might help the surgeon remove more of the tumour, and so prolong patients' survival.

So far, there is no convincing proof that this method is better than standard surgery for patients with high-grade brain tumours such as glioblastoma multiforme.

Equipment for doing MRI during surgery is not yet widely available in Australia.

Safety issues for MRI

Before an MRI, all metal objects must be removed from the person's body. MRI cannot be used for people with metal inside their bodies, such as:

- permanent clips used in surgery for aneurysm
- cardiac pacemakers
- cochlear implants
- a tiny speck of metal inside the eyeball (e.g. due to an accident).

Nuclear medicine

Nuclear imaging (an older type of scan) is no longer used much in patients with brain tumours, because it has been replaced by CT and MRI.

Some new nuclear imaging techniques, such as neuro-SPECT^{viii} and neuro-PET^{ix} can be useful:

- before biopsy, to help find the best site to target when taking the specimen
- before surgery, to get more information about the type of tumour (before a specimen is available)
- after surgery, to tell how far the tumour has spread
- after radiotherapy, to tell the difference between damage caused by the radiation and malignant tumour
- in follow-up, to detect whether a low-grade tumour has changed to become higher grade (growing more rapidly).

^{viii} Single photon emission computed tomography of the brain

^{ix} Positron emission tomography of the brain

Brain scans after treatment for a brain tumour

After surgery

After surgery to remove a brain tumour, brain scans can be also used to look for tumour that has been left behind.

An MRI 24–48 hours after surgery helps detect changes that are due to the surgery, such as bleeding. These scans can be kept as a record so that, months or years later, the abnormal appearance caused by surgery will not be mistaken for signs that the tumour has changed to become higher grade (more rapidly growing).

Follow-up imaging

MRI is the best type of brain scan for follow-up after treatment for a brain tumour.

A follow-up MRI is usually done 6–12 weeks after a person has received radiotherapy for a brain tumour, then repeated every two-to-three months. If the tumour shows no signs of growing or worsening over a long period, MRI might be repeated less often (for example every six months).

Limits of brain scans

Brain scans cannot always give clear information about a tumour. For example:

- It is not possible to be sure that an abnormal area of brain seen on CT or MRI is definitely a brain tumour, even when there are also symptoms that could be due to a brain tumour. For an accurate diagnosis, it is usually necessary to examine a piece of tumour (collected by biopsy or surgery) under the microscope.
- CT and MRI give reliable information about some aspects of brain tumours, but do not give accurate information about the type of brain tumour.
- When changes in brain tissue are seen at follow-up after treatment for a brain tumour, it might not be possible to tell whether these are caused by treatment (such as damage caused by radiation), or by the tumour growing and worsening.

6. Pathology and diagnosis

Key points

- Before doctors can give advice about treatment, an accurate diagnosis of the type of brain tumour must be made by taking a specimen and having it examined by an experienced pathologist.
- The pathologist will require as much information as possible when examining the tissue specimen to make an accurate diagnosis.
- The final diagnosis by the pathologist may take several days, because there are several steps involved in processing the tissue and then examining it.
- Pathologists use the internationally accepted World Health Organization classification system to make the diagnosis of the tumour type and its grade.
- The grade of the tumour gives an indication of whether it is likely to grow slowly or quickly.
- It is possible for the diagnosis made by a pathologist to be inaccurate. This is uncommon.
- Genetic testing of the tumour specimen is recommended for all oligodendrogliomas.
- Patients may be asked to donate any leftover tumour for research.

Why it is important to take a specimen

Normally, a person will not receive treatment for a brain tumour until the diagnosis has been confirmed; doctors are sure that the abnormal growth is a tumour, and that they know what type of tumour it is.

A brain tumour cannot be accurately diagnosed without examining a piece of the tumour under a microscope. The information from symptoms, physical examination, brain scans and blood tests is important when making the diagnosis, but is not as reliable as the information from a specimen.

For most patients with a brain tumour, a specimen will be taken in one of two ways:

- needle biopsy – a small piece is taken through a small hole in the skull
- surgical biopsy – a larger piece is taken during a surgical procedure, which aims to remove as much of the tumour as possible.

If it is too dangerous to remove a specimen, doctors may have to treat the person without this information. This happens very rarely.

What happens in the pathology laboratory

The specimen is thoroughly examined in the pathology laboratory by a pathologist. Brain tumour specimens should be examined by a specialist pathologist with expertise and experience in brain tumours (a neuropathologist).

The pathologist should be given as much clinical information as possible to help them make an accurate diagnosis. Patients can help by making sure their neurosurgical team has all the information about their medical history, including all previous treatments.

During surgery

Sometimes the pathologist examines part of a specimen immediately, so that a preliminary diagnosis can be made while the surgeon is still operating.

Examining a sample in this way is called a “frozen section” because the piece of tumour is snap-frozen to make it easier to slice and handle. This is only possible when there is enough tumour to use some for frozen section, while keeping the remainder for standard methods of microscopic examination and testing.

The frozen section technique can provide some useful early information to the surgeon about the type of tumour, or confirm that the growth is a tumour and not due to an infection or some other cause. This information is not as reliable as information from the full testing process, so the pathologist may make a different final diagnosis hours or days later.

Processing the specimen

The final diagnosis may take several days, because it involves several steps, including:

- soaking the piece of tumour in preservative (‘fixing’)
- embedding the preserved tissue in paraffin wax, then cutting it into very thin slices (taking ‘sections’)
- applying special dyes to sections to highlight different features and structures (‘staining’)
- examining stained sections under the microscope using accepted international standards
- doing special tests, if required
- making a report.

Slices taken from all parts of the removed tumour must be examined carefully, because different areas within the same tumour may have different grades (see *Making the diagnosis*, later in this chapter).

Making the diagnosis

Pathologists use an internationally accepted system (World Health Organization classification of tumours^x) to make the diagnosis of tumour type.

The diagnosis will usually include the grade of the tumour. The tumour grade gives an indication of how quickly the tumour is growing, which is important in predicting the person’s outlook for survival. The grade is usually a number between one (I) and four (IV). In general:

- A grade I or grade II tumour is slow growing.

^x The International Agency for Research on Cancer. *WHO classification of tumours of the central nervous system* (Fourth Edition). Geneva; WHO: 2007

- A grade III or grade IV tumour is growing more quickly.

Sometimes a tumour can contain areas with different grades. The highest grade determines the behaviour of the tumour and the outlook from treatment.

The pathology report

In the pathology report the pathologist records all the information gained from examining the piece of tumour, including:

- what the tumour looked like to the naked eye
- what the processed tumour tissue looked like under the microscope
- which stains were used and what they revealed
- the tumour type
- the tumour grade
- any special features that could give information about the person's outlook, such as the percentage of cells that are actively growing and dividing ('proliferation index').

Patients can ask their specialists for a copy of their pathology report.

Accuracy of the diagnosis

It is possible for the pathologist's diagnosis to be inaccurate, but this is uncommon.

For example, if the piece of tumour sent to the pathology laboratory is very small, (e.g. a needle biopsy specimen) it may not be a good example of the whole tumour – especially if the tumour has different regions in it, with some growing faster than others. This means the remaining tumour that was not removed during surgery could be different from the piece examined by the pathologist.

When deciding the best treatment for a person with a brain tumour, doctors may also consider other factors besides the pathology diagnosis, such as symptoms and brain scans. For example, if the pathologist has made the diagnosis of a grade II (slow-growing) tumour, but brain scans show that the person's tumour is growing rapidly, doctors may decide it is better to treat it as a higher grade tumour.

Pathologists may not always agree about the diagnosis. When this happens, they may ask for a second opinion from a neuropathologist at another hospital or from an expert centre overseas.

Special tests that provide more information

Sometimes extra tests are done on a tumour specimen.

Currently, the information available from genetic testing of tumours does not make a substantial difference to the diagnosis or treatment for people with most types of brain tumours. However, genetic testing is recommended for people with oligodendrogliomas. In oligodendrogliomas, certain abnormalities in two chromosomes (deletion of the short arm of chromosome 1 [1p] and the long arm of chromosome 19 [19q]) may indicate the person has a better prognosis than if their tumour does not have these features. It may also help predict that the person will benefit from treatment.

In people with high-grade astrocytomas (also called glioblastoma multiforme), a test that shows whether the enzyme MGMT^{xi} is chemically 'switched off' (methylated) may provide information about prognosis after radiotherapy or chemotherapy. This test is not widely available now, but may become available for standard testing in future.

Tissue banking and clinical trials

Patients may be asked to give permission to donate any leftover pieces of their tumour to be stored for future research ('tissue banking'). There are strict protocols for tissue banking:

- The person's permission must be given before doctors can store any tissue or blood.
- Tissue is only stored after enough has been collected to examination and diagnosis.
- The donation is usually de-identified, so researchers handling the specimen do not know the person's name.

Patients should ask their neurosurgeon if they are not sure about any aspect of tissue donation.

Patients have the right to be given any extra information about their tumour from genetic tests or other tests that were done on their donated samples.

If a person has agreed to participate in a clinical trial, a piece of their tumour, or slices on glass slides, may be sent for testing to a different laboratory. (There is more information about clinical trials in **Chapter 3. Participating in brain tumour research.**)

^{xi} MGMT is the abbreviation for the O⁶-methylguanine-methyltransferase enzyme.

7. Low-grade astrocytomas

Key points

Diagnosis

- Before being diagnosed with a low-grade astrocytoma, a person will usually need to undergo brain scans, including magnetic resonance imaging (MRI), and have a specimen of tumour examined in the pathology laboratory. A reliable diagnosis cannot be made from brain scans alone.
- Needle biopsy is a fairly safe method of collecting a brain tumour specimen, but is not as reliable for making the diagnosis as a specimen taken during brain surgery.

Treatment

- Doctors should explain all the treatment options clearly, with their possible benefits and side effects.
- The main options for treating a person with a low-grade astrocytoma are surgery and radiotherapy.
- If a patient chooses to have surgery, it may be best to do surgery soon after the diagnosis.
- Surgery is a less suitable option if the tumour is small, spread throughout healthy brain tissue (diffuse), and in an area of the brain where surgery would be too risky.
- If surgery has relieved a person's symptoms and the tumour has temporarily stopped growing or slowed down, then radiotherapy can usually be delayed until the tumour starts growing or becomes more invasive.
- Radiotherapy may be the best option when there are clear signs that the tumour is growing or becoming more invasive, but surgery is not possible.
- Radiotherapy immediately after surgery for a low-grade astrocytoma is unlikely to make someone live longer, but it might give them more time before the tumour becomes more invasive.
- After the treatment options have been explained, with their possible benefits and side effects, some patients might choose not to have surgery or radiotherapy at first. It is reasonable to delay treatment, especially when surgery is not the best option.
- When the tumour shows signs of growing and becoming more invasive, treatment is usually recommended to minimise the risk of permanent brain damage.

Background facts

Astrocytoma is one of the most common types of brain tumours. Astrocytomas are graded from one to four. A grade two (II) astrocytoma is “low-grade”. It grows more slowly than a high-grade tumour, but may later change to become a higher-grade tumour. (There is more information about grades of tumours in **Chapter 1. Basic facts** and **Chapter 6. Diagnosis and pathology**.)

Low-grade astrocytomas are less common than high-grade astrocytomas. (There is information about high-grade astrocytomas in **Chapter 8. High-grade astrocytomas**.)

How doctors diagnose a low-grade astrocytoma

Symptoms of low-grade astrocytoma

About half of all people with low-grade astrocytoma have epilepsy (recurring seizures) before the tumour is diagnosed. Other common symptoms include headache, changes in thinking and behaviour, and problems with brain function. (There is more information about symptoms of brain tumours in **Chapter 4. Symptoms of brain tumours.**)

If there is a possibility that someone has a brain tumour, doctors will arrange for brain scans to be done.

Imaging (brain scans)

When doctors suspect that a person has a brain tumour, the first scan is often done using computed tomography (CT). CT scans may reveal an abnormal area in the brain, but may not clearly show that the abnormality is a brain tumour. When this happens, doctors will usually arrange for the person to have an MRI. (There is more information about CT and MRI in **Chapter 5. Imaging.**)

MRI is the best type of scan for diagnosing low-grade astrocytoma. Compared with other types of scans, MRI is better at identifying abnormal brain tissue that could turn out to be a low-grade astrocytoma. Tumours and areas of swelling around them due to fluid build up (oedema) can be seen more clearly with MRI than with CT.

Surgical removal of a tumour specimen

It is not possible for doctors to be completely sure that a person has a low-grade astrocytoma just by doing a scan such as MRI or CT. Doctors generally agree that the most accurate way to make the diagnosis is by taking a specimen of tumour and sending it to the pathology laboratory.

Careful examination of the tumour cells under a microscope (histopathology) is the best way to be sure that the tumour is a low-grade astrocytoma and to work out whether it is low grade or high grade. (There is more information about how pathologists diagnose brain tumours from tumour specimens in **Chapter 6. Diagnosis and pathology.**)

The tumour specimen can be taken either by removal of a very small piece through a small hole in the skull (needle biopsy), or during surgery ‘open resection’ when a larger part of the tumour is removed (surgical biopsy).

Which type of specimen gives the most accurate diagnosis?

It is important to make an accurate diagnosis, so decisions about the best way to treat the tumour can be based on the most reliable information.

Specimens taken during open resection surgery give the most reliable information. Needle biopsy is a less accurate method, because the very small piece taken may be different from the rest of the tumour. In many people (about half of people with gliomas), the diagnosis made after brain surgery is different from the earlier diagnosis made after needle biopsy.

Surgical removal of a specimen is not a suitable option for some people. (There is more information about surgery later in this chapter.)

Is biopsy safe?

Having a biopsy is generally associated with a low level of risk that would be acceptable to most people.

However, biopsy might be too risky in some rare situations. Major side effects due to brain damage could occur due to biopsy if the tumour is in or near an area of the brain that is critical for normal living (e.g. the brainstem) or essential for a particular function (e.g. speech or movement). People with low-grade astrocytoma that is spread out (diffuse) may experience worse symptoms after a needle biopsy.

Treatment for people with low-grade astrocytomas

The options for managing a low-grade astrocytoma include surgery and radiotherapy, either alone or combined. The role of chemotherapy is still under investigation.

Each option has advantages and disadvantages. Medical experts do not fully agree about which is the best way to manage low-grade astrocytoma.

Before starting treatment

Patients with a low-grade astrocytoma should expect their doctors to explain the diagnosis and treatment options clearly and with compassion. The doctor should make sure the patient, family and carers understand which treatment options are available, and should explain the possible advantages and disadvantages of each. The choice of what to do next may not be easy to make.

A doctor should not make decisions alone about which treatments to recommend, but should discuss the person's treatment plan with all the doctors, nurses and other health professionals involved in caring for that person.

Surgery

Surgery is a suitable option for some patients with low-grade astrocytoma. The benefits and risks of surgery for low-grade astrocytoma depend on how widespread the tumour is and which part of the brain it is in.

Brain surgery for patients with low-grade astrocytoma involves standard microsurgery techniques. During the operation, surgeons normally use special scanning devices and computers during the operation to help find the exact target position within the brain. This method, called stereotactic guidance, should be used where available.

Sometimes surgery is done while the person is awake, so that the surgeon can check whether the area of tumour to be removed is close to areas of the brain that are crucial for certain functions. This method helps avoid damaging important areas of healthy brain, and can help reduce the chances of permanent brain damage after the operation.

Aims of surgery

The aim of surgery is to remove as much of the tumour as possible, while minimising damage to surrounding healthy brain. Cure is usually not the aim; unfortunately, there is only a very low chance of removing enough of the tumour to completely cure the person.

Sometimes it is not possible to remove all visible tumour, due to the risk of causing brain damage. On average, the more tumour is left behind, the sooner it is likely to grow, and the shorter time the person has to live. Removal of as much tumour as possible might also make the tumour less likely to become invasive, but there is not strong evidence for this.

Sometimes the main reason for attempting surgical removal of the tumour is to reduce swelling in or around the brain or to improve epilepsy. Occasionally, people with advanced cancer and limited life expectancy may have surgery to relieve their symptoms, with the aim of making them more comfortable towards the end of their life. This situation is rare.

When is the best time for surgery?

If the person chooses surgery, there are several reasons why it may be better for this to take place soon after diagnosis:

- A specimen can be taken at the same time and examined by a pathologist, to be certain that the diagnosis of low-grade astrocytoma is correct.
- Early surgery may help reduce or control symptoms.
- Early surgery might help prolong survival if all of the visible tumour can be removed.
- Early surgery might make the tumour less likely to become more malignant.

When surgery is not the best option

If the tumour is in an area of the brain that is critical for normal living or essential for a particular function (e.g. speech or movement), it may be difficult for the surgeon to remove the tumour without causing significant brain damage. Doctors are less likely to recommend surgery as the best option if the tumour is small, spread throughout healthy brain tissue (diffuse), or in an area of the brain where damage is likely to be debilitating to the person.

Some doctors recommend that surgery for low-grade astrocytoma should be avoided, because there is no clear evidence that surgery will benefit most people.

Radiotherapy

Radiotherapy (using X-rays to kill tumour tissue) can be used:

- immediately after surgery as another method of attempting to stop the tumour worsening
- when the tumour is growing or becoming more invasive, and surgery is unsuitable.

The main aims of early radiotherapy for people with low-grade astrocytoma are to delay tumour growth and control symptoms such as seizures. Early radiotherapy immediately after the diagnosis does not seem to prolong survival in people with low-grade astrocytoma (see Box 7.1), but it does increase the time before the tumour grows and worsens.

Like other cancer treatments, radiotherapy has side effects that need to be considered when deciding between treatment options (see Box 7.2).

Before giving a person radiotherapy for low-grade astrocytoma, doctors need to consider:

- the best time to do radiotherapy
- the right dose for the person
- the target area in the brain
- possible side effects such as brain damage.

Box 7.1. What is the evidence for the benefits of radiotherapy?

The most useful evidence for the possible benefits of radiotherapy in people with low-grade astrocytoma comes from a large international clinical trial conducted by the European Organisation for Research and Treatment of Cancer (EORTC). A group of over 300 people who had just had surgery for low-grade astrocytoma were divided into two groups; one group received radiotherapy immediately, and the other group did not. People in the second group could opt for radiotherapy later after their tumour showed signs of growing, and 65% of them did receive delayed radiotherapy.

The results of this trial showed that early radiotherapy:

- slowed down the growth of tumours, but did not stop them eventually worsening
- helped control epileptic seizures
- did not increase survival time.

Based on this clinical trial, radiotherapy seems to be equally effective for prolonging survival in people with low-grade astrocytoma, whether it is given early or delayed until the tumour worsens.

When is the best time for radiotherapy?

Doctors generally agree that, for most people with low-grade astrocytoma, it is best not to give radiotherapy immediately after initial surgery, which is usually soon after the diagnosis. Instead, it can be given later when symptoms worsen or a scan shows that the tumour has grown or changed. This opinion is based on evidence that radiotherapy given immediately after surgery does not make people with low-grade astrocytoma survive longer than people who wait, even though it can delay tumour growth.

However, early radiotherapy is recommended for certain groups of people with low-grade astrocytoma. These groups include:

- people who have a high risk that their tumour will soon begin growing and becoming more invasive, and who therefore have a worse chance of survival.
- people with low-grade astrocytoma in the brainstem (the area of the brain just above the spinal cord). Usually, these people are already experiencing symptoms at the time of diagnosis, and surgery is not an option because it would be too dangerous.

Doctors generally agree that radiotherapy is suitable when there is clear evidence that a person's tumour is growing – such as worsening symptoms (e.g. more frequent seizures) or scan results – but no other treatment can be used.

Side effects of radiotherapy

Although radiotherapy is aimed at the tumour, it affects surrounding healthy tissue as well.

There is not enough reliable evidence to tell whether modern radiotherapy causes significant brain damage and disability in people with low-grade astrocytoma. Available evidence is mainly from older studies, in which the patients received radiotherapy techniques that are no longer standard (see Box 7.2).

Box 7.2. What is the evidence that radiotherapy causes brain damage?

Overall, evidence from medical research suggests that:

- side effects of radiotherapy probably depend on a person's age (older patients may have a higher risk), the doses of radiation given at each time, the total dose of radiation they received, and the timing of chemotherapy (if given)
- radiotherapy probably increases a person's risk of having problems in ability to think, remember, solve problems and reason (cognitive function), especially problems with memory. However, the risk of developing memory problems is higher for people who have higher doses of radiation (more than 2 Gy^{xii} in one dose).

Brain tumours can cause the same problems, so it is not possible to be sure when radiotherapy is the cause.

There is not yet enough evidence to know what side effects might show up in people with low-grade astrocytoma who survive more than five years after radiotherapy.

Waiting (conservative approach)

After the benefits and risks of surgery have been explained, some patients and their families might choose to avoid surgery and instead wait to see if the tumour grows or causes problems before they have treatment. This might be a reasonable option if:

- the risks of surgery have been explained and are unacceptable for the person
- the risks of waiting have been explained and are acceptable for the person
- the tumour is small
- the tumour is not easy to remove (e.g. the MRI scan shows that it is spread throughout healthy brain tissue, or is in an area of the brain where damage could cause significant disability, such as the brainstem).

Waiting to see whether the tumour grows or becomes more invasive before having surgery also has risks. There is some evidence that, on average, people who wait until there are signs that the tumour is growing or becoming more invasive, (e.g. waiting until they experience symptoms or a scan shows that the tumour is bigger or has changed) may experience earlier worsening of the tumour and die sooner than people who choose early treatment.

Another argument against delaying surgery is that the person loses the chance to have the tumour size surgically reduced so that their symptoms do not get worse over time. This is a

^{xii} The standard unit for measuring radiation is the Gray (abbreviated as Gy).

case of weighing up the risk of brain damage due to surgery against the risk of brain damage due to the tumour itself.

If a person chooses to wait, treatment (surgery or radiotherapy) will usually be needed when the tumour grows and becomes more invasive. Once there is evidence that the tumour is growing and becoming more malignant, the person should be offered treatment soon, before the tumour causes irreversible brain damage.

Chemotherapy

There is not enough evidence to be sure which patients with low-grade astrocytoma will benefit from chemotherapy, or when it should be given. Chemotherapy can involve various combinations of different drugs, so it is sometimes not possible to compare the results of different studies.

Chemotherapy can be given as an additional treatment with radiotherapy. There is not enough evidence to recommend this for most people with low-grade astrocytoma. Some small studies have reported benefits in people with low-grade astrocytoma who received chemotherapy when their tumour recurred after other treatment, or who received it before radiotherapy. In some studies, people who received chemotherapy as well as radiotherapy experienced a longer time before their tumour progressed (grew larger or became more invasive) than people who received radiotherapy only, but they did not live longer.

An international clinical trial is comparing radiotherapy with temozolomide (a type of chemotherapy) in people who have just had surgery for low-grade astrocytoma. The results are not available yet.

Chemotherapy has side effects, because it can damage healthy tissue as well as the tumour. Common side effects of chemotherapy include nausea and vomiting, loss of appetite, tiredness and lack of energy, and infections. These problems can be managed effectively.

More information

A booklet about chemotherapy (*Understanding chemotherapy. A guide for people with cancer, their families and friends*), is available from www.cancercouncil.com.au or Cancer Council Helpline 13 11 20

8. High-grade astrocytomas

Key points

- High-grade astrocytomas are the most common types of brain tumours.

Diagnosis

- The best type of brain scan for diagnosing high-grade astrocytoma is MRI performed after dye has been injected into the person's bloodstream (contrast-enhanced MRI). All patients with a suspected brain tumour should have contrast-enhanced MRI unless it would be unsafe for them.
- The most accurate way to make the diagnosis of high-grade astrocytoma is by taking a specimen of tumour and sending it to the pathology laboratory (biopsy). All patients should have a biopsy before treatment begins, if possible.

Treatment

- High-grade astrocytomas may be treated with surgery, radiotherapy, chemotherapy or a combination of these. Decisions about treatment are often complex and may involve a number of specialists as well as the patient and their family or carers.
- The best care for a person with a high-grade astrocytoma involves teamwork by neurosurgeons, radiation and medical oncologists, neurologists, neuropathologists, psychiatrists, rehabilitation specialists, neuroscience nurses and allied health professionals such as physiotherapists and occupational therapists (multidisciplinary care).
- Surgery should be done to remove as much tumour as possible for all patients with high-grade astrocytomas who are well enough to undergo an operation. Surgery may prolong survival.
- Chemotherapy wafers can be inserted into the cavity left behind after the tumour is surgically removed. This type of chemotherapy can prolong survival by about 8–12 weeks in people with glioblastoma multiforme.
- Radiotherapy is recommended for all people with high-grade astrocytomas if they are well enough to have this treatment, because it can prolong their survival by up to twice as long.
- Radiotherapy should start as soon as possible after the diagnosis of high-grade astrocytoma – usually two-to-six weeks after surgery, when the surgical wound has healed. For people with high-grade astrocytoma who are fit enough, the recommended standard total dose of radiotherapy is 60 Gy, given in 30 daily doses of 2 Gy at a time over about six weeks.
- There is no evidence that stereotactic radiosurgery, gamma-knife surgery or brachytherapy (special techniques for increasing the dose of radiotherapy to the tumour) can prolong survival in patients with high-grade astrocytomas.
- For elderly patients who are mildly disabled, or patients with significant disabilities, shorter courses of radiotherapy have been used, but this is generally not recommended because current evidence shows that shorter courses are less effective than full courses.

- Chemotherapy is recommended for all patients with grade IV astrocytoma (glioblastoma multiforme) who are well enough, because it can prolong survival. It should begin at the same time as radiotherapy and continue for six months after radiotherapy (Stupp protocol).
- Chemotherapy is recommended for all patients with grade III astrocytoma (anaplastic astrocytoma). Researchers are currently investigating temozolomide as a possible choice of chemotherapy for these patients.
- A high-grade astrocytoma may recur after initial treatment with surgery, radiotherapy and chemotherapy. Treatment decisions are difficult when this happens, because there is no clear evidence for which treatment is best.

Treatment after tumour recurrence

- Surgery – if technically feasible – is usually recommended for people with recurrent high-grade astrocytomas who have no or few symptoms of the tumour, and are otherwise well, because it may improve symptoms and quality of life. However, surgery may not be possible if the tumour is in an area of the brain that would make the operation too risky.
- Chemotherapy may benefit people with recurrent high-grade astrocytomas who have no or few symptoms due to the tumour and are otherwise well. It may control symptoms and maximise quality of life.

Background facts

Astrocytoma is one of the most common types of brain tumours. (There is more information about types of brain tumours in **Chapter 1. Basic facts**.)

Astrocytomas are graded from one to four (I–IV). A grade three (III) or four (IV) astrocytoma is “high-grade”. They grow more rapidly and are more invasive (malignant) than a low-grade tumour. (There is more information about grades of tumours in **Chapter 1. Basic facts** and **Chapter 6. Diagnosis and pathology**.)

High-grade astrocytomas are the most common types of brain tumours. They typically occur in people aged 50–70 years, and are slightly more common in men than in women. In most patients there is no known cause, but in a small minority the tumour is due to an inherited genetic condition or previous exposure to high doses of radiation, such as previous treatment for another cancer in childhood. (There is more information about known causes of malignant brain tumours in **Chapter 1. Basic facts**.)

How doctors diagnose a high-grade astrocytoma

Symptoms of high-grade astrocytoma

Symptoms that lead to the diagnosis of high-grade astrocytoma differ between individuals, depending on the location of the tumour in the brain and how fast the tumour is growing.

The most common symptoms include headache, confusion and memory loss. Seizures are also common. Some people develop symptoms similar to a stroke, with numbness or difficulty speaking.

Symptoms usually develop over weeks to months, but occasionally they begin very suddenly. (There is more information about symptoms of brain tumours in **Chapter 4. Symptoms of brain tumours.**)

Imaging (brain scans)

When doctors suspect that a person has a brain tumour, the first scan is often done using computed tomography (CT). CT scans may reveal an abnormal area in the brain, but may not clearly show that the abnormality is a brain tumour. When this happens, doctors will usually arrange for the person to have a scan using magnetic resonance imaging (MRI). (There is more information about CT and MRI in **Chapter 5. Imaging.**)

The best type of brain scan for diagnosing high-grade astrocytoma is MRI performed after dye has been injected into the person's bloodstream (contrast-enhanced MRI). All patients with a suspected brain tumour should have an MRI unless it would be unsafe for them. (There is more information about safety issues for MRI in **Chapter 5. Imaging.**)

Surgical removal of a tumour specimen

It is not possible for doctors to be completely sure that a person has a high-grade astrocytoma just by doing CT and MRI scans. Doctors generally agree that the most accurate way to make the diagnosis is by taking a specimen of tumour and sending it to the pathology laboratory.

Careful examination of the tumour cells under a microscope (histopathology) is the best way to be sure that the tumour is a high-grade astrocytoma. (There is more information about how pathologists diagnose brain tumours from tumour specimens in **Chapter 6. Pathology and diagnosis.**)

The tumour specimen can be taken by removing a very small piece through a small hole in the skull (needle biopsy). More commonly, a larger biopsy specimen is taken during surgery to remove the tumour ('open resection').

Sometimes a biopsy is not done if a person is very elderly or too unwell to receive treatment, so the exact diagnosis will make no difference to their care.

Is biopsy safe?

Having a biopsy is generally associated with a low level of risk that would be acceptable to most people.

However, biopsy might be too risky in some rare situations. Major side effects due to brain damage could occur due to biopsy if the tumour is in or near an area of the brain that is critical for normal living or essential for a particular function (e.g. speech or movement). There is a high risk of complications due to biopsy if the tumour is in the brainstem (the area of the brain above the spinal cord, which is critical for survival).

Diagnosis by the pathologist

After examining the specimen under the microscope and doing any other tests, the pathologist diagnoses the type of tumour and its grade. (There is more information about how

pathologists diagnose brain tumours from tumour specimens in **Chapter 6. Pathology and diagnosis.**)

High-grade astrocytomas include:

- grade III astrocytomas (also called anaplastic astrocytomas)
- grade IV astrocytomas (also called glioblastoma multiforme [GBM]).

In general, grade IV astrocytomas have a more serious prognosis than grade III astrocytomas. However, survival differs between individuals.

Recent research suggests that genetic features of tumours are also important for the person's outlook, and not just the grade based on the microscopic appearance of the tumour.

A grade IV astrocytoma can either begin growing inside a low-grade astrocytoma that has already been in the brain for some time, or begin growing as a new grade IV tumour on its own. Even though they both have the same name and grade, they may be genetically different, grow differently and have a different prognosis for the person's survival. In future, differences like this may help doctors choose the best treatment.

Prognosis

For a person with a high-grade astrocytoma, it is important to predict the person's outlook for survival as accurately as possible so that decisions about treatment can be based on realistic expectations. Most people would want to avoid long courses of treatment that are inconvenient and could have unpleasant side effects, if they knew that the treatment was unlikely to make them live any longer or feel better.

Although treatments are becoming more effective, people with high-grade astrocytomas generally have a low chance of survival. On average:

- about one in three (36%) patients survives two years after the diagnosis
- about one in four (28%) patients survive five years after the diagnosis
- among people with a grade IV astrocytoma (the most malignant form), about one in four (27%) who receive treatment with both radiotherapy and chemotherapy survives two years after the diagnosis.

Some people survive much longer than these times. In general, factors that indicate the person has a better chance of surviving longer include:

- age younger than 60 years
- being generally healthy and fit
- having seizures for more than three months at the time of diagnosis
- normal brain function, including cognition (thinking, memory and alertness), movement, speech and balance
- grade III astrocytoma (anaplastic astrocytoma)
- surgical removal of all visible tumour (or the more removed, the better).

In general, patients with high-grade astrocytoma are likely to have a worse outlook if they are older, have a grade IV astrocytoma (glioblastoma multiforme), and have abnormal brain function or significant disabilities due to the tumour or other illnesses.

None of these factors on its own can give much information about the outlook. Several groups of researchers have attempted to develop scoring systems for predicting a person's survival mathematically, based on these factors. There are more details about how doctors work out an individual's prognosis in the Australian glioma management guidelines for doctors.^{xiii}

Before starting treatment

Treatment cannot begin until the diagnosis is confirmed, because all treatments for high-grade astrocytoma have serious side effects.

Patients with a high-grade astrocytoma should expect their doctors to explain the diagnosis and treatment options clearly and with compassion. The doctor should make sure the patient, family and carers understand which treatment options are available, and should explain the possible advantages and disadvantages of each.

The choice of what to do next may not be easy to make, because there are complex factors to consider and several specialists will be involved in planning treatment, as well as the patient and their family or carers.

A doctor should not make decisions alone about which treatments to recommend, but should discuss the person's treatment plan with all the doctors, nurses and other health professionals involved in caring for that person.

Initial treatment for people with high-grade astrocytomas

High-grade astrocytomas may be treated with surgery, radiotherapy, chemotherapy or a combination of these.

The best care for a person with a high-grade astrocytoma involves teamwork by neurosurgeons, radiation and medical oncologists, neurologists, neuropathologists, psychiatrists, rehabilitation specialists, neuroscience nurses and allied health professionals such as physiotherapists and occupational therapists (multidisciplinary care). In rural and remote regions of Australia, a person may need to travel to a major city for surgery, but might prefer to receive most of their postoperative and ongoing care from a smaller local team at a regional hospital or within their own community, if possible.

Surgery

People with high-grade astrocytomas should have surgery to remove as much tumour as possible, because this could prolong their survival. Surgery is recommended for anyone who is fit to undergo an operation, regardless of their age.

Surgery may not be possible if the person is too unwell, the tumour is in a position that would make surgery too risky, or the tumour is too big.

^{xiii} Australian Cancer Network Adult Brain Tumour Guidelines Working Party. *Clinical practice guidelines for the management of adult gliomas: astrocytomas and oligodendrogliomas*. Sydney; Cancer Council Australia, Australian Cancer Network and Clinical Oncological Society of Australia Inc: 2009.

Brain surgery for patients with high-grade astrocytoma involves standard microsurgery techniques. During the operation, surgeons normally use special scanning devices and computers during the operation to help find the exact target position within the brain. This method, called stereotactic guidance, should be used where available.

Sometimes surgery is done while the person is awake, so that the surgeon can check whether the area of tumour to be removed is close to areas of the brain that are crucial for certain functions. This method helps avoid damaging important areas of healthy brain, and can help reduce the chances of permanent brain damage after the operation.

Brain surgery should only be performed at a hospital that has the appropriate equipment and trained staff, and where the person can be cared for by a team of health professionals with a range of different specialised skills. Only a small number of public and private hospitals in Australia can perform brain surgery.

Hospitals that perform brain surgery must meet strict safety and quality standards, including requirements for operating rooms, equipment and technology. These are outlined in Australian glioma management guidelines for doctors.^{xiv}

Aims of surgery

The aim of surgery is to remove as much of the tumour as possible, while minimising damage to surrounding healthy brain. Cure is usually not the aim; unfortunately, it is not possible to remove enough of the tumour to completely cure the person. The surgeon attempts to remove all the tumour that is visible to the naked eye, as well as all tumour visible on MRI scan taken two-to-three days before surgery.

In some cases it is not safe to remove all visible tumour because it is too close to important areas of healthy brain.

Other aims of surgery are:

- to provide a large specimen for examination by the pathologist, to confirm the diagnosis and help guide treatment
- to relieve the pressure on the brain. This can improve symptoms and may reduce the amount of dexamethasone the person needs to control symptoms
- to reduce the amount of remaining tumour to be treated with radiotherapy and chemotherapy. These treatments may be better tolerated and have less side effects if there is less tumour left to treat.

Inserting chemotherapy wafers

Implants containing a chemotherapy drug can be inserted into the cavity left by the tumour that has been removed. These implants, known as ‘chemotherapy wafers’, are made of sterile plastic and contain carmustine (brand name Gliadel).

^{xiv} Chapter 8. High grade astrocytoma, in Australian Cancer Network. Adult Brain Tumour Guidelines Working Party. *Clinical practice guidelines for the management of adult gliomas: astrocytomas and oligodendrogliomas*. Sydney; Cancer Council Australia, Australian Cancer Network and Clinical Oncological Society of Australia Inc: 2009.

The use of chemotherapy wafers can prolong survival by about 8–12 weeks in people with a new diagnosis of glioblastoma multiforme or when glioblastoma multiforme has recurred after initial treatment.

Chemotherapy wafers may increase the risk of complications after surgery, such as infections of the wound, slow healing of the wound, and leakage of fluid from around the brain (cerebrospinal fluid) through the wound.

The availability of chemotherapy wafers is restricted in Australia because they are very expensive.^{xv}

There is not enough evidence yet to know whether there is an advantage in having chemotherapy wafers implanted during surgery as well as having standard chemotherapy. It is not known if chemotherapy wafers are safe when used in combination with other chemotherapy or radiotherapy, or whether they provide any additional benefit to this combination treatment.

Radiotherapy

Radiotherapy (using X-rays to kill tumour tissue) is recommended for anyone who is well enough to have this treatment, regardless of their age. People with high-grade astrocytomas should have radiotherapy after surgery, because it could prolong their survival (Box 8.1).

Patients who are severely disabled are unlikely to benefit from radiotherapy.

The decision whether to have radiotherapy is more difficult for patients who are young but have severe disabilities, or very old with mild disabilities, because it is not clear that these groups will benefit as much as patients with less disability.

Box 8.1. What is the evidence for radiotherapy?

- There is strong evidence that radiotherapy prolongs survival in patients with high-grade astrocytomas. Several high-quality clinical trials involving a large number of patients have compared surgery alone with surgery plus radiotherapy. Overall, they show that radiotherapy can enable people to survive twice as long, on average, after the diagnosis.
- There is less evidence for whether effectiveness is different for people with grade III astrocytomas compared with people with grade IV astrocytomas. These groups were not compared separately in early clinical trials. In some clinical trials, similar benefits were seen in both groups. After radiotherapy, people with grade III tumours will probably still survive longer than people with grade IV tumours, even if both groups live longer than they would have without radiotherapy.
- The findings of some studies have suggested that the sooner radiotherapy is given, the longer the person will survive. However, this evidence is not conclusive.

^{xv} The cost of Gliadel is subsidised by the Pharmaceutical Benefits Scheme (PBS) or Repatriation Pharmaceutical Benefits Scheme at the time of initial surgery for people with suspected or confirmed glioblastoma multiforme, but the PBS subsidy is only available in private hospitals and for outpatients. A patient cannot receive this subsidy at the same time as receiving a subsidy for temozolomide, another chemotherapy drug. Gliadel is not currently subsidised for patients having surgery in public hospitals.

- Several high-quality studies involving a large number of patients with high-grade astrocytomas have compared different doses of radiotherapy. Overall, the results showed that a total dose of 60 Gy improves survival time by about an extra one-third compared with 50 Gy. A total dose of 70 Gy is no better than 60 Gy. Therefore, 60 Gy is recommended as the optimal dose.
- Different schedules have also been studied. These include giving two or more smaller doses (fractions) per day several hours apart ('hyperfractionation') and giving two or more standard-sized fractions per day ('accelerated fractionation'). Neither hyperfractionation nor accelerated fractionation seem to be any more effective in improving survival time than giving one fraction per day. Therefore, 2 Gy per day has been accepted as the standard.
- Some studies have investigated whether radiotherapy for less than six weeks is still effective for people with a poor prognosis, including older patients, disabled patients and patients with grade IV tumours. These studies have not provided conclusive evidence that shorter courses are as effective as the standard six weeks.

Recommended schedule for radiotherapy

Radiotherapy should start as soon as possible after the diagnosis of high-grade astrocytoma – usually two-to-six weeks after surgery, when the surgical wound has healed.

The recommended standard total dose of radiotherapy for high-grade astrocytoma is 60 Gy,^{xvi} given in 30 daily doses of 2 Gy at a time over about six weeks. This dosing schedule is only used for people who are fit and well enough to tolerate the treatment.

Experts have agreed on this dose of radiation after balancing the doses needed to kill the tumour and the need to minimise possible damage to healthy brain near the tumour. Giving small doses allows the brain to recover between doses.

For patients who are older and mildly disabled, or have significant disabilities, shorter courses of radiotherapy might still be effective. However, shorter courses are not generally recommended, based on current evidence.

Other radiotherapy techniques

Several techniques have been developed with the aim of increasing the dose of radiotherapy to the tumour without damaging the surrounding normal brain. These include:

- stereotactic radiosurgery (using computer technology to focus very high doses of radiotherapy onto a small area of the tumour)
- gamma-knife surgery (similar to stereotactic radiosurgery)
- brachytherapy (placing small radioactive pellets into the tumour during surgery).

These techniques have mainly been tried in younger, healthier patients. Overall, there is no evidence that these techniques prolong survival time in patients with high-grade astrocytomas.

^{xvi} The standard unit for measuring radiation is the Gray (abbreviated as Gy).

The higher amount of radiation often caused swelling in the brain, so patients needed prolonged dexamethasone therapy. Dexamethasone has significant side effects. (There is more information about dexamethasone in **Chapter 11. Managing symptoms and complications.**)

Chemotherapy

Chemotherapy slightly increases survival time in people with high-grade astrocytomas (Box 8.2).

Chemotherapy is recommended for all patients with grade IV astrocytoma (glioblastoma multiforme) who are well enough to undergo chemotherapy. Chemotherapy should begin at the same time as radiotherapy and continue for six months after radiotherapy. This treatment method, which is called the Stupp protocol, prolongs survival.

Chemotherapy is recommended for all patients with grade III astrocytoma (anaplastic astrocytoma) who are well enough to undergo chemotherapy. If chemotherapy is used, it should be given after radiotherapy. The Stupp protocol is not recommended because it has not been tested in this group and may have side effects that cannot be justified in people who survive several years after treatment.

The Stupp protocol is not recommended for patients with high-grade astrocytoma who are elderly or disabled. It has not been tested in these groups. Chemotherapy given after radiotherapy may benefit these patients, but there is not much evidence.

There is no evidence that giving chemotherapy for longer than six months will improve survival even more.

Temozolomide is commonly used for chemotherapy in patients with brain tumours, because it is very well tolerated and it is the most effective drug.

Box 8.2. What is the evidence for chemotherapy?

- Many clinical trials have tested different chemotherapy drugs in people with high-grade astrocytomas. When all the results are analysed together, they show that chemotherapy slightly improves survival time: for every 100 patients treated, an extra 6 would still be alive after one year, compared with giving no chemotherapy.
- For patients with grade III astrocytoma (anaplastic astrocytoma) in these trials, chemotherapy slightly increases survival time: for every 100 patients treated, an extra five would still be alive after one year, and an extra six would still be alive after two years, compared with giving no chemotherapy.
- A high-quality clinical trial in patients with grade IV astrocytoma (glioblastoma multiforme) compared two groups of patients after surgery: both groups had radiotherapy. In one group, temozolomide chemotherapy was given at the same time as radiotherapy and continued for six months afterwards. After two years, 27% of the group who had radiotherapy plus chemotherapy were still alive, compared with only 10% of the group who had radiotherapy alone.
- There also is a small amount of evidence that elderly patients may benefit from temozolomide chemotherapy after radiotherapy, even if temozolomide has not been given during radiotherapy.

Managing high-grade astrocytomas that recur after initial treatment

A high-grade astrocytoma may ‘recur’ (or grow back) after initial treatment with surgery, radiotherapy and chemotherapy.

Treatment decisions are difficult when this happens, because there is a lack of high-quality evidence for which treatment is best, and there are different definitions of recurrence (Box 8.3).

Ideally, people with recurrent high-grade astrocytomas should be offered the chance to participate in clinical trials of new treatments. (There is more information about clinical trials in **Chapter 3. Participating in brain tumour research.**)

Box 8.3. Terms and definitions for tumour recurrence

- **Radiological recurrence** means that a brain scan shows the tumour has grown, but the person has no new symptoms.
- **Clinical recurrence** means that the person has developed new symptoms that suggest the tumour is worsening. Brain scans confirm that the tumour is growing.
- **Recurrence** is often used to mean a tumour has worsened after a period of control after treatment. However, it has not actually ‘re-occurred’ or ‘returned’, because it was never truly eradicated; a tiny amount of tumour was still inside the brain all along, even if invisible on brain scans.
- **Progression** means that a tumour is growing or has changed to become a higher grade, which means it is behaving less like normal brain tissue and is becoming more invasive (malignant).
- **Pseudo-progression** means the tumour appeared to be worsening on MRI after radiotherapy and chemotherapy, but then later appeared to be improved on a later MRI. In this situation the tumour has not actually worsened, and its appearance was misleading because of changes in appearance due to the treatment.

Confirming that the tumour has recurred

After radiotherapy and chemotherapy, a brain scan using MRI can be difficult to interpret because of changes caused by treatment. Sometimes the tumour may appear worse initially then show improvement on later MRIs (pseudo-progression).

It may be difficult for the radiologist to tell the difference between pseudo-progression and true progression. If new areas of tumour can be seen outside the area that was treated with radiation, the tumour is probably worsening.

Surgery for a recurring tumour

Surgery is often used to treat a person with a high-grade astrocytoma that has recurred (is progressing). In this situation, the aims of surgery are usually:

- to delay the onset of symptoms
- to reduce the size of the tumour before further chemotherapy.

Surgery is usually recommended for people who are young, have no or few symptoms of the tumour, and are otherwise well.

There is not enough evidence to know whether second surgery is likely to make a person survive longer than they would without surgery, or by how long. However, most doctors agree it may improve a person's symptoms and quality of life.

The effectiveness of second surgery has not been assessed in older or more disabled patients.

The possible risks of surgery must be considered for all patients.

Chemotherapy for a recurring tumour

Chemotherapy is often recommended for people with a high-grade astrocytoma that has recurred after initial treatment, especially those who are young, have no or few symptoms of the tumour, and are otherwise well.

There is some evidence that chemotherapy may prolong survival, but this has not been proven. The aim of chemotherapy is mainly to control symptoms and maximise quality of life.

Temozolomide is commonly used for chemotherapy in patients with recurrent brain tumours, because it is very well tolerated.

If the tumour has recurred or progressed very quickly while the person is still taking temozolomide, the medical oncologist may consider changing the dose or switching to a different chemotherapy drug or combination.

Box 8.4. What is the evidence for chemotherapy after recurrence?

Overall, clinical studies in people with recurrent high-grade astrocytomas treated with various chemotherapy drugs suggest that:

- About one third (35%) of people with recurrent grade III astrocytoma (anaplastic astrocytoma) will benefit from chemotherapy (e.g. the tumour may shrink or temporarily stop growing)
- Only about one fifth (20%) of people with recurrent grade IV astrocytoma (glioblastoma multiforme) will benefit from chemotherapy
- People who benefit are likely to experience improved quality of life or delay worsening quality of life.
- For temozolomide chemotherapy, longer dosing schedules are not clearly more effective than standard dosing schedules.
- Combinations of chemotherapy drugs may be slightly more effective than treatment with one drug, but increase the risk of side effects.

New treatments

New treatments are under investigation for the treatment of recurrent high-grade astrocytomas, either alone or in combination with chemotherapy. These include:

- thalidomide^{xvii}
- bevacizumab (brand name Avastin).

Bevacizumab prevents tumour growth by preventing new blood vessels forming in the tumour. In preliminary studies, it appeared to be potentially effective and well tolerated when used alone or in combination with irinotecan (a chemotherapy drug used in bowel cancer). Bevacizumab can reduce the amount of corticosteroid medicine that a patient needs to control symptoms. At present, it is unclear whether bevacizumab prolongs survival.

^{xvii} Thalidomide is not currently registered in Australia for use in the treatment of patients with brain tumours. It is used in the treatment of blood cancer and skin conditions. It is available through special access schemes at the patient's own cost.

9. Oligodendrogliomas

Key points

Diagnosis

- The number of people diagnosed with an oligodendroglioma each year has increased in recent years because doctors' understanding and awareness of this type of tumour has improved.
- Oligodendroglioma are classified as either low grade or high grade.
- Some patients have a combination of oligodendroglioma and astrocytoma in the same tumour (oligoastrocytoma).
- Brain scans can be used to make the initial diagnosis and can provide useful information about the person's prognosis, but a biopsy is always necessary to confirm the diagnosis and do genetic testing.

Genetic testing and prognosis

- Pathologists should do genetic testing for "1p/19q co-deletion" on all biopsy specimens from patients with oligodendrogliomas or oligoastrocytomas, because the result will help predict the outcome.
- Some people live for many years after the diagnosis. The chance of survival is better for low-grade tumours than high-grade tumours, and better for tumours that test positive for the 1p/19q co-deletion than tumours that test negative.

Treatment

- For people with low-grade oligodendroglioma, the aim of treatment is to control the tumour for as long as possible. Many people live many years or decades with this type of tumour.
- Surgery is the usual treatment for oligodendrogliomas and oligoastrocytomas. If safe, surgical removal of as much tumour as possible may prolong survival time.
- Radiotherapy is a standard treatment for low-grade oligodendrogliomas and oligoastrocytomas, but it can be difficult to know whether it is best to have this treatment immediately after surgery or wait until the tumour grows and worsens.
- The standard dose of radiotherapy is a total of 50 Gray over six weeks, in daily doses of no more than 2 Gray.
- Having regular checkups and brain scans, instead of radiotherapy, is a reasonable option for a person with a low-grade oligodendroglioma or oligoastrocytoma who has a good chance of surviving for several years.
- Chemotherapy may be effective for some patients with low-grade oligodendrogliomas or oligoastrocytomas, but it is not a proven treatment. People are more likely to benefit from chemotherapy if genetic testing shows that their tumour has the 1p/19q co-deletion.

- Chemotherapy immediately after surgery and radiotherapy is not recommended as standard treatment for patients with newly diagnosed high-grade oligodendrogliomas or oligoastrocytomas, because it does not improve overall survival, compared with initial radiotherapy alone.

Treatment after tumour recurrence

- If a high-grade oligodendroglioma or oligoastrocytoma recurs a long time after the initial treatment, doctors may consider recommending a second course of radiotherapy, if the person is fit and well.
- Chemotherapy is often recommended for people with a high-grade oligodendroglioma or oligoastrocytoma that has recurred after initial treatment, especially those who are fit and well.

Background facts

Oligodendroglioma is one of the less common types of brain tumours. (There is more information about types of brain tumours in **Chapter 1. Basic facts.**)

The number of people diagnosed with an oligodendroglioma each year has increased in recent years because doctors' understanding and awareness of this type of tumour has improved. The internationally accepted definition of oligodendroglioma has recently been changed. This definition is important, because oligodendrogliomas generally have a better prognosis than other gliomas.

Oligodendrogliomas are classified as one of two grades:

- grade two (II) – low grade
- grade three (III) – high grade, also called anaplastic oligodendroglioma.

Low-grade oligodendrogliomas occur mainly in people in their late thirties and early forties. High-grade (anaplastic) oligodendrogliomas mainly occur in people in their late forties and early fifties. Oligodendrogliomas are slightly more common in men than women. (There is more information about grades of tumours in **Chapter 1. Basic facts** and **Chapter 6.**

Diagnosis and pathology.)

Oligodendrogliomas can also be mixed with astrocytomas (called oligoastrocytomas).

How doctors diagnose an oligodendroglioma

Symptoms of oligodendroglioma

Seizures occur in the majority (up to 70%) of people with oligodendrogliomas. A seizure is commonly the first symptom. Often a person has had seizures over a long period before receiving the diagnosis.

Some people have no symptoms, and their tumour is discovered by accident when a radiologist checks a scan done for another reason (such as a minor head injury or sinus pain).

Symptoms depend on where the tumour is located in the brain. Oligodendrogliomas can occur anywhere in the brain, but are common in the frontal lobes and near the surface of the brain. (There is more information about symptoms of brain tumours in **Chapter 4. Symptoms of brain tumours.**)

Imaging (brain scans)

When doctors suspect that a person has a brain tumour, the first scan is often done using computed tomography (CT). CT scans may reveal an abnormal area in the brain, but may not clearly show that the abnormality is a brain tumour. When this happens, doctors will usually arrange for the person to have another scan using magnetic resonance imaging (MRI). (There is more information about CT and MRI in **Chapter 5. Imaging.**)

CT and MRI brain scans in people with oligodendrogliomas (especially grade II tumours) typically show that the tumour is in the outermost layer of the brain (the cerebral cortex). There may be a build-up of calcium within the tumour. When these features are seen on a brain scan, the person probably has an oligodendroglioma, but it is not a certainty.

It can be difficult to assess how rapidly an oligodendroglioma is growing and how malignant it is from CT and MRI brain scans. Low-grade oligodendrogliomas often have a high concentration of blood vessels, which is usually typical of high-grade tumours. Doctors do not rely on brain scans to find out what grade the tumour is.

Because brain scans only give limited information, it is always necessary to examine a specimen of tumour in the pathology laboratory.

Surgical removal of a tumour specimen

It is not possible for doctors to be completely sure that a person has an oligodendroglioma from brain scans alone. Doctors generally agree that the most accurate way to make the diagnosis is by taking a specimen of tumour and sending it to the pathology laboratory. Even when typical features of an oligodendroglioma are seen on CT and MRI, a specimen is still needed to confirm the diagnosis and enable genetic testing to be done.

Before beginning treatment, all patients with a suspected oligodendroglioma or oligoastrocytoma should have a specimen taken. The tumour specimen can be taken either by removal of a very small piece through a small hole in the skull (biopsy), or during surgery when a larger part of the tumour is removed ('open resection').

Specimens taken during open resection surgery give the most reliable information. Needle biopsy is a less accurate method, because the very small piece taken may be different from the rest of the tumour. In many people (about half of people with gliomas), the diagnosis made after brain surgery is different from the earlier diagnosis made after biopsy.

Surgical removal of a specimen is not a suitable option for some people. (There is more information about surgery later in this chapter.)

Having a biopsy is generally associated with a low level of risk that would be acceptable to most people. However, biopsy might be too risky in some rare situations. Major side effects due to brain damage could occur due to biopsy if the tumour is in or near an area of the brain that is critical for normal living or essential for a particular function (e.g. speech or movement).

Grading

Careful examination of the tumour cells under a microscope (histopathology) is the best way to be sure that the tumour is an oligodendroglioma and to work out whether it is low grade or high grade. (There is more information about how pathologists diagnose brain tumours from tumour specimens in **Chapter 6. Diagnosis and pathology**.)

It is relatively straightforward for a pathologist to recognise grade II oligodendrogliomas when they have typical features. It can be much more difficult to recognise high-grade oligodendrogliomas and mixed tumours that contain both astrocytoma and oligodendroglioma (oligoastrocytomas).

Because oligodendrogliomas can be difficult to diagnose accurately using standard pathology methods, genetic methods have been developed.

Genetic testing

Pathologists should do genetic testing for “1p/19q co-deletion” on all biopsy specimens from patients with oligodendrogliomas or oligoastrocytomas.

1p/19q co-deletion is a genetic feature of most, but not all, oligodendrogliomas. It means that a section is missing on each of two chromosomes (the short ‘arm’ of chromosome 1 [1p] and the long arm of chromosome 19 [19q]). In general, people with an oligodendroglioma that has 1p/19q co-deletion have a better response to treatment and have a better prognosis than people with oligodendrogliomas that do not have this genetic feature.

Prognosis

Oligodendrogliomas have a better prognosis than astrocytomas, especially for low-grade oligodendrogliomas:

- For people with grade II (low-grade) oligodendrogliomas, median^{xviii} survival time after diagnosis is seven years. This means that half of these people survive for more than seven years.
- For people with grade III (high-grade) oligodendrogliomas, median survival time after diagnosis is 11–14 months. This means that half of these people survive for more than 14 months.

A positive test for the 1p/19q co-deletion means there is a better chance for surviving longer. Among people with grade II (low-grade) oligodendrogliomas:

- for those with 1p/19q co-deletion, median survival time after diagnosis is 13 years. This means that half of these people survive for more than 13 years.
- for those without 1p/19q co-deletion, median survival time after diagnosis is nine years. This means that half of these people survive for more than nine years.

Among people with grade III (high-grade) oligodendroglioma, on average:

- about 74% of those with the 1p/19q co-deletion survive for five years after the diagnosis

^{xviii} The median is the midpoint between the shortest and longest survival time when all survival times are listed in order.

- about 27% of those without 1p/19q co-deletion survive for five years after the diagnosis.

Before starting treatment

Treatment should not begin until the diagnosis is confirmed.

Patients with an oligodendroglioma should expect their doctors to explain the diagnosis and treatment options clearly and with compassion. The doctor should make sure the patient, family and carers understand which treatment options are available, and should explain the possible advantages and disadvantages of each.

The choice of what to do next may not be easy to make, because there are complex factors to consider and several specialists will be involved in planning treatment, as well as the patient and their family or carers.

A doctor should not make decisions alone about which treatments to recommend, but should discuss the person's treatment plan with all the doctors, nurses and other health professionals involved in caring for that person.

Treatment for low-grade oligodendrogliomas or oligoastrocytoma

Treatments for oligodendroglioma are unlikely to cure the tumour. The aim of treatment is to control the tumour for as long as possible and maximise the person's comfort and quality of life.

The options for managing oligodendroglioma include surgery, radiotherapy and chemotherapy. The best treatment for an individual depends on all the available information about the tumour, including its grade and genetics, and the person's condition. Treatments, and the order in which they are given, are tailored for each person to maximise the benefits while minimising side effects.

For people with low-grade oligodendrogliomas, surgery is the usual treatment, and radiotherapy may also be recommended. Many people live for many years or decades with this type of tumour.

A doctor should not make decisions alone about which treatments to recommend, but should discuss the person's treatment plan with all the doctors, nurses and other health professionals involved in caring for that person.

Surgery

Surgery to remove as much tumour as possible is recommended. Overall, the available evidence suggests that surgery can make people survive longer, but there have not been many high-quality studies assessing surgery for oligodendroglioma.

When should surgery be done?

For patients with low-grade oligodendroglioma or oligoastrocytoma, surgery to remove the tumour is usually not urgent because they have no symptoms interfering with everyday life and the tumour is not growing rapidly. For many people, a seizure has been the only symptom

of the tumour. Some patients have no symptoms at all, if the diagnosis was made on a scan taken for another reason.

However, there is a possibility that a higher-grade tumour may have been missed on the scan, especially in patients older than 40 years. Delaying surgery might risk losing the opportunity to take a specimen that could provide a correct diagnosis. In patients who have chosen not to have surgery immediately, a surgical biopsy should still be taken soon after the diagnosis based on the brain scan.

When surgery is not the best option

Surgical removal may not be possible if the tumour is large, spread throughout the brain, or too close to healthy brain and surgery would risk causing significant brain damage. When surgical removal of the tumour is not possible or too risky, a small piece (biopsy) should be taken as a specimen for testing.

Aims of surgery

The surgeon's aim is to remove all tumour that is visible to the naked eye and all seen on brain scans. However, it is not possible to remove all tumour cells.

Waiting (conservative approach)

After the benefits and risks of surgery have been explained, some patients and their families might choose not to have surgery to remove the tumour. This might be a reasonable option if a biopsy has confirmed that the tumour is low grade and other tests show that the person has a good prognosis.

People with oligodendrogliomas who choose not to have surgery soon after diagnosis should have regular MRI and medical checks.

Radiotherapy

Radiotherapy (using X-rays to kill the tumour) is a standard treatment for people with oligodendrogliomas or oligoastrocytomas.

Although the effectiveness of radiotherapy for oligodendrogliomas and oligoastrocytomas is not completely proven, there is evidence that it may delay the growth of low-grade tumours and control symptoms.

When should radiotherapy begin?

Although radiotherapy is standard treatment, doctors do not agree about whether it should be given immediately after surgery, or delayed until a brain scan shows that the tumour is growing.

There is some evidence that radiotherapy given soon after surgery can delay regrowth of the tumour and improve control of seizures, but does not prolong survival (Box 9.1).

Because people with oligodendroglioma can survive for many years after radiotherapy, the long-term side effects of treatments must be considered. Some doctors prefer not to

recommend radiotherapy immediately after surgery because it may cause side effects months or years after treatment. In the past, the main concern has been about possible problems with memory and thinking capacity (neurocognitive dysfunction). However, the risk of brain damage is probably low with modern radiotherapy, which uses lower doses and targets the dose to the tumour.

Currently, radiotherapy immediately after surgery is mainly recommended:

- for patients who still have a large amount of tumour that could not be removed surgically
- to control symptoms, including seizures
- for older patients.

Delaying radiotherapy and waiting to see if it worsens is a reasonable option for some patients. This might be recommended for patients:

- with no symptoms due to the tumour
- with a good prognosis for a long survival (including a positive genetic test for 1p/19q co-deletion)
- younger than 40 years
- who have had all the visible tumour successfully removed at surgery.

The tumour will usually continue to grow slowly, with an average increase in diameter of 4 mm per year. People who do not have radiotherapy immediately after surgery should have regular brain scans with MRI.

Recommended dose for radiotherapy

The recommended dose of radiotherapy dose is a total of 50 Gy,^{xix} given in doses (called 'fractions') of 2 Gy at a time over six weeks.

This dose is effective while maximising safety. Patients should not receive more than 2 Gy on one day.

Box 9.1. What is the evidence for the benefits of radiotherapy?

It is difficult to know which is the best treatment for people with oligodendroglioma or oligoastrocytomas, because radiotherapy for brain tumours has mainly been tested in studies that include all types of low-grade gliomas, including astrocytomas. Overall, the results of radiotherapy clinical trials suggest that:

- In people with low-grade tumours, it makes no difference to overall survival time whether they have radiotherapy soon after surgery or wait until later when the tumour shows signs of worsening. However, radiotherapy soon after surgery can delay regrowth of the tumour and help control seizures.
- In people with low-grade oligodendrogliomas, a total dose of 50 Gy is effective. Higher doses have no extra benefit.

^{xix} The standard unit for measuring radiation is the Gray (abbreviated as Gy).

Chemotherapy

For some patients with low-grade oligodendrogliomas or oligoastrocytomas, chemotherapy may reduce the size of the tumour, but it is not a proven treatment. Chemotherapy is more likely to be effective if genetic testing shows that the tumour has the 1p/19q co-deletion (Box 9.2).

There is not enough information from clinical trials to know how effective chemotherapy is compared with radiotherapy, or whether the side effects are any better or worse than with radiotherapy. Clinical trials are underway to compare chemotherapy and radiotherapy in people with low-grade gliomas.

Box 9.2. What is the evidence for chemotherapy?

There is no clear evidence for the benefits of chemotherapy given immediately after diagnosis in people with oligodendrogliomas or oligoastrocytoma. Overall, the evidence suggests that:

- in people with low-grade tumours, chemotherapy with temozolomide is more likely to be effective if genetic testing shows that their tumour has the 1p/19q co-deletion
- in people with high-grade tumours, chemotherapy given immediately after diagnosis is more effective in delaying tumour growth if the tumour has tested positive for the 1p/19q co-deletion. However, the benefit is still no better than with radiotherapy given immediately, followed by chemotherapy given later, and survival is not prolonged.
- in people with high-grade tumours that have tested negative for the 1p/19q co-deletion, neither chemotherapy nor radiotherapy is very effective in delaying tumour growth
- PCV,^{xx} an older type of chemotherapy, has significant side effects.

Treatment for high-grade oligodendrogliomas or oligoastrocytoma

Surgery

Surgery to remove as much tumour as possible is generally recommended for people with high-grade oligodendroglioma. Surgery is usually followed by radiotherapy.

Radiotherapy

Radiotherapy is standard treatment for people with high-grade oligodendrogliomas or oligoastrocytomas.

Chemotherapy

Chemotherapy immediately after surgery and radiotherapy is not recommended as standard treatment for patients with newly diagnosed high-grade oligodendrogliomas or

^{xx} PCV stands for the combination of procarbazine, lomustine (also called CCNU) and vincristine

oligoastrocytomas. However, new evidence from clinical trials may provide more information in the near future.

In the past, a combination of three chemotherapy drugs known as PCV^{xxi} was commonly used in addition to radiotherapy for people with high-grade oligodendrogliomas and oligoastrocytomas. Early use of PCV is no longer recommended as a standard treatment for patients with high-grade oligodendrogliomas or oligoastrocytomas, because there is more recent evidence that early use of this treatment does not increase survival compared with radiotherapy alone, and that it has significant side effects.

Chemotherapy with either PCV or temozolomide may be used in the treatment of recurrent or rapidly growing tumours. (There is more information about treating tumours that have recurred later in this chapter.)

Follow-up

Patients with oligodendrogliomas or oligoastrocytomas should continue to have regular MRI scans after treatment.

For people with low-grade oligodendrogliomas or oligoastrocytomas, follow-up will normally involve having an MRI every few months. If they remain well over a long period and brain scans do not show that the tumour is growing or worsening, it might be safe to have brain scans just once every year.

For people with high-grade oligodendrogliomas or oligoastrocytomas, follow-up will normally involve having an MRI every three months at first, then every six months if the tumour is stable.

People who have had seizures may need more frequent follow-up visits. (There is more information about follow-up after a brain tumour in **Chapter 14. Follow-up.**)

Managing oligodendrogliomas that recur after initial treatment

An oligodendroglioma or oligoastrocytoma may ‘recur’ after initial treatment. This may be discovered during a regular brain scan, or because the person develops symptoms (Box 9.3).

Treatment decisions are difficult when this happens, because there is a lack of high-quality evidence for which treatment is best.

Ideally, people with recurrent high-grade oligodendrogliomas or oligoastrocytomas should be offered the chance to participate in clinical trials of new treatments. (There is more information about clinical trials in **Chapter 3. Participating in brain tumour research.**)

^{xxi} procarbazine, lomustine (also called CCNU) and vincristine

Box 9.3. Terms and definitions for tumour recurrence

- **Radiological recurrence** means that a brain scan shows the tumour has grown, but the person has no new symptoms.
- **Clinical recurrence** means that the person has developed new symptoms that suggest the tumour is worsening. Brain scans confirm that the tumour is growing.
- **Recurrence** is often used to mean a tumour has worsened after a period of control after treatment. However, it has not actually ‘re-occurred’ or ‘returned’, because it was never truly eradicated; a tiny amount of tumour was still inside the brain all along, even if invisible on brain scans.
- **Progression** means that a tumour is growing or has changed to become a higher grade, which means it is behaving less like normal brain tissue and is becoming more invasive (malignant).

Surgery for a recurring tumour

Surgery might be considered for a person with a high-grade oligoastrocytoma that has recurred or is growing (progressing). In this situation, the aims of surgery are usually:

- to delay the onset of symptoms
- to reduce the size of the tumour before chemotherapy.

Surgery is usually recommended for people who have no or few symptoms of the tumour, and are otherwise well.

However, surgery may not be possible if the tumour is spread out, or if it is in an area that would make the operation too risky.

There is not enough evidence to know whether second surgery is likely to make a person survive longer than they would without surgery, or by how long. However, most doctors agree it may improve a person’s symptoms and quality of life.

The effectiveness of second surgery has not been assessed in older or more disabled patients.

The possible risks of surgery must be considered for all patients.

Radiotherapy for a recurring tumour

If high-grade oligodendroglioma or oligoastrocytoma recurs a long time after the initial treatment, doctors may consider recommending a second course of radiotherapy, if the person is fairly fit and well.

Chemotherapy for a recurring tumour

Chemotherapy is often recommended for people with a high-grade oligodendroglioma or oligoastrocytoma that has recurred after initial treatment, especially those who are fairly fit and well. There is some evidence that chemotherapy with various drugs may prolong survival, but this has not been proven. The aim of chemotherapy is mainly to control symptoms and maximise quality of life.

The main factor that predicts whether chemotherapy will be helpful when the tumour has progressed or recurred is whether or not the person's tumour has tested positive for the 1p/19q co-deletion.

High-grade oligodendrogliomas and oligoastrocytomas that have recurred after initial radiotherapy will often respond to chemotherapy, especially if the person has not had previous chemotherapy.

Chemotherapy may also be considered for low-grade oligodendrogliomas that are progressing (growing or changing), particularly if the patient is developing new symptoms such as weakness or seizures, or if existing seizures have become more difficult to control. However, there is no single recommended standard treatment for recurring low-grade oligodendroglioma, because there is not much clear evidence about which treatment is most effective.

Even people who have had chemotherapy earlier in their treatment may benefit from a second course of chemotherapy with either the same chemotherapy drug (or combination), or a different drug.

10. Complementary, alternative and unproven therapies

Key points

- Complementary therapies are promoted for use alongside conventional effective anticancer treatments, and include treatments that have been shown to improve wellbeing or reduce symptoms.
- ‘Alternative’ therapies include unproven treatments that are promoted as a substitute for conventional cancer treatments with claims that they affect tumour growth.
- There is no high-quality medical evidence that any complementary or alternative therapies are effective in shrinking or slowing the growth of brain tumours.
- There is high-quality evidence from many studies that counselling can improve people’s feeling of wellbeing, although it does not affect survival.
- Relaxation techniques can reduce stress and pain, and improve quality of life in people with cancer.
- There is good evidence that acupuncture can help control symptoms of nausea and vomiting and improve quality of life during chemotherapy.
- Massage therapy might help control cancer pain for some people.
- Herbal remedies containing ginger may be effective in reducing nausea.
- Cannabis may be effective in reducing nausea and vomiting, but may have side effects.
- Herbal remedies containing valerian may help with insomnia.
- There is no convincing evidence that homeopathy is effective in the care of people with cancer.
- Like all medicines, complementary and alternative medicines may have harmful effects, including serious side effects.
- People with brain tumours who are interested in complementary and alternative therapies should talk to their doctors about possible benefits and risks.

Background

Despite continuing improvements in medical treatment for people with gliomas, many patients still face premature death or debilitating symptoms. Patients and their families or carers often look for complementary and alternative therapies outside the mainstream health system (Box 10.1).

Complementary and alternative therapies are popular in Australia and other countries including the USA, UK and other European countries. Surveys in patients with cancer have found that among people with any type of cancer, the majority use complementary and alternative therapies. Among people with primary brain tumours, many use complementary and alternative therapies. Most of these people do not tell their doctor that they are using these therapies.

Types of therapies used by people with brain tumours may include:

- medicines that are injected or taken orally, including products made from plants or animals (such as traditional Chinese medicines or Ayurvedic medicines), vitamins, pharmaceutical products that are not usually used in cancer treatment
- special diets
- acupuncture
- massage and touch therapies
- psychological therapy including counselling, group therapy, relaxation, hypnosis, meditation and spiritual healing
- homeopathy
- non-invasive medical devices or procedures such as low-intensity alternating electrical fields.

People who use these therapies often feel that conventional medicine has failed to cure their cancer. They may hope or believe that complementary and alternative therapies will be more effective in prolonging their life or improving their symptoms. Some are looking for treatments that are less toxic or have fewer side effects than conventional treatments such as radiotherapy or chemotherapy.

Many people with cancer say that they use complementary and alternative therapies because it helps them feel hopeful about their future. Some say that choosing to use these therapies makes them feel they have more control over decisions about their medical care.

Box 10.1. Some terms and definitions

“Complementary and alternative medicine” refers to the wide range of health care systems, practices and products that are not currently considered to be part of conventional medicine.

Complementary therapies are treatments that are used alongside conventional medical care (e.g. psychological counselling), with the aim of improving health or reducing side effects of treatment.

Alternative therapies include unproven treatments that are promoted as a substitute for conventional cancer treatments.

Possible benefits of complementary and alternative medicine

Effectiveness against the cancer

There is no high-quality medical evidence that any complementary or alternative therapies are effective in shrinking or slowing the growth of brain tumours.

Better quality of life

Psychological therapies

Counselling is an accepted component of mainstream cancer care for people with cancer. There is high-quality evidence from many studies that counselling can improve people's feeling of wellbeing, although it does not affect survival.

Meditation and relaxation

The aims of meditation are to achieve relaxation and/or spiritual goals. There are also specific relaxation techniques that do not involve meditation. Clinical trials show that relaxation techniques can reduce stress and pain, and improve quality of life in people with cancer.

Acupuncture

There is good evidence that acupuncture can help control symptoms of nausea and vomiting, and improve quality of life during chemotherapy. The findings of several clinical trials show that conventional acupuncture can reduce the likelihood of experiencing nausea the day after chemotherapy (but not throughout the chemotherapy course), and that electro-acupuncture can reduce the likelihood of vomiting the day after chemotherapy.

Many clinical trials have tested other effects of acupuncture in patients with cancer, but the results have been conflicting.

Massage

There is a small amount of evidence that massage therapy may be helpful in managing cancer pain and reducing anxiety in people with cancer.

A clinical trial in patients with cancer found that six weeks of aromatherapy massage was effective in helping to reduce symptoms of anxiety and depression, but there was no benefit after 10 weeks.

Aromatherapy

A clinical trial in patients found that people who had aromatherapy during their radiotherapy showed higher levels of anxiety than people who did not receive aromatherapy. Another clinical trial showed that it increased nausea experienced by patients having chemotherapy.

However, there is some evidence that aromatherapy massage can be effective in helping to reduce symptoms of anxiety and depression in people with cancer (see Massage).

Herbal remedies

There is some evidence that ginger may be effective in controlling nausea caused by cancer and its treatment.

The results of several clinical trials have shown that cannabis may be effective in reducing nausea and vomiting caused chemotherapy. However, there is no evidence that it has any benefit over standard anti-emetic medicines, and it has side effects.

Herbal remedies containing valerian may be effective in managing insomnia.

The herb *Boswellia serrata* (common names include frankincense and salai) may help reduce swelling in the brain in people who are receiving radiotherapy.

Homeopathy

There is no convincing evidence that homeopathy is effective in the care of people with cancer.

Homeopathic remedies are very unlikely to cause harm, because the active ingredient is extremely diluted.

Other potential benefits

People with cancer who use complementary and alternative therapies may experience improvements in symptoms or feelings of wellbeing due to the placebo effect.

They might also gain a sense of hope, a feeling that they are more in control of their health care.

Possible unwanted effects

Like all medicines, complementary and alternative medicines may have harmful effects, including serious side effects. People who use these products should understand that:

- many ‘natural’ remedies are not tested for safety like registered medicines, so the side effects may not be known or difficult to find out about
- the ingredients of complementary and alternative medicines can react with prescription medicines and cause extra side effects or make medicines less effective
- some herbal remedies and dietary supplements could contain impurities or drugs that could be harmful. There is more risk with medicines that are not regulated by the Therapeutic Goods Administration,^{xxii} such as those bought over the internet.

Other problems for people with brain tumours using complementary and alternative therapies can include the extra expense, and false hope if the person has unrealistic expectations.

People with brain tumours who are interested in complementary and alternative therapies should talk to their doctors about possible benefits and risks. It is important for patients to tell doctors about any complementary and alternative treatments they are using, in case these interact with other treatments.

Reliable information about the effectiveness and safety of complementary and alternative therapies for people with cancer is available from several reputable organisations (Box 10.2).

^{xxii} In Australia, Listed and Registered medicines are labelled AUST L and AUST R. These labels do not mean that a complementary medicine is effective.

More information

A booklet about complementary medicines (*Understanding complementary therapies. A guide for people with cancer, their families and friends*), is available from www.cancercouncil.com.au or Cancer Council Helpline 13 11 20

Box 10.2. Where to find reliable information

These organisations provide reliable information about complementary and alternative therapies for people with cancer:

The Cancer Council Australia: www.cancercouncil.org.au

MD Anderson Cancer Center (USA): www.mdanderson.org/departments/CIMER/

Memorial Sloan-Kettering Cancer Center (USA): www.mskcc.org

The National Institute of Health (USA): nccam.nih.gov

11. Managing symptoms and complications

Key points

Seizures

- Seizures may be due to the tumour itself or due to surgery. For some people with brain tumours, seizures are their main disability or only symptom.
- Treatment with an anticonvulsant medicine should be started after the first seizure in a person with a brain tumour.
- Starting anticonvulsant treatment before a person has a seizure is not recommended
- Some anticonvulsant medicines (carbamazepine and phenytoin) can reduce the effectiveness of other medicines, such as corticosteroids (e.g. dexamethasone), warfarin, oral contraceptives and some chemotherapy drugs.
- If a person taking anticonvulsant medicines has no seizures for a long time, it may be possible to gradually reduce the medicine over two-to-three months under medical supervision, then stop.
- When a person with a brain tumour has experienced a seizure, their doctors or other health professionals should advise them and their families or carers about first aid for seizures, driving restrictions, how to avoid seizures, and the probability that their seizures will be successfully controlled.
- There are national standards for drivers with epilepsy (recurring seizures), which apply in every state and territory and are enforceable by law. There are also driving restrictions for people with brain tumours.

Skin reactions due to cancer treatments

- In a person taking anticonvulsant medicines, skin reactions can sometimes be a sign of a serious medical problem affecting the kidneys and liver. Patients should tell their doctor immediately if they develop a rash during the first few months of taking an anticonvulsant medicine. Blood tests should be done to check liver and kidney function.
- Short-term skin damage due to radiation can be relieved by applying a fragrance-free, non-irritant moisturiser regularly.

Blood clots

- Blood clots in the legs or lungs are common in people with brain tumours.
- Treatment with heparin (usually given by injection under the skin) is recommended to prevent blood clots in most people with a glioma, especially those most at risk because they are elderly, unable to walk much, or have a high-grade tumour. Preventive heparin treatment may need to be continued indefinitely.
- Treatment with heparin or enoxaparin (given by daily injection under the skin) is recommended to treat blood clots in people with gliomas. Some people may also need to take warfarin tablets afterwards. The length of warfarin treatment depends on the individual's level of risk.

Dexamethasone

- Treatment with dexamethasone is recommended for people who have swelling (oedema) in the brain that can be seen on brain scans, and who have symptoms due to the swelling. It is not normally given if the oedema is seen on a scan but the person has no symptoms.
- Dexamethasone is also used to help prevent oedema in people who have radiotherapy to a large part of the brain.
- After starting dexamethasone, the dose should be gradually reduced until the person is taking the lowest amount that will still control their symptoms.
- If possible, dexamethasone treatment should be gradually stopped after the person has finished radiotherapy. Dexamethasone treatment should not be stopped suddenly. It should be reduced over several weeks (or even over months for some people).
- Dexamethasone can cause significant side effects. Patients and their families or carers should be given written information about this medicine.
- In patients taking dexamethasone, treatment with a proton pump inhibitor medicine should be given to prevent stomach ulcers and bleeding inside the stomach if the person is also taking medicine to prevent blood clots or has had a stomach ulcer in the past.
- In patients taking dexamethasone, treatment to prevent osteoporosis should be considered for all postmenopausal women, and in men and pre-menopausal women who have thin bones.
- Antibiotics to prevent pneumonia caused by *Pneumocystis* may be given to patients receiving dexamethasone radiotherapy and temozolomide chemotherapy at the same time.

Seizures

Up to 40% of people with gliomas have seizures at the time of diagnosis, and about 10–15% develop seizures later, during treatment. Seizures at the time of diagnosis are more likely in younger people and people with low-grade tumours. (There is more information about which types of tumours are most likely to cause seizures in **Chapter 4. Symptoms of brain tumours.**)

Several types of seizures can occur:

- simple partial seizure – the person stays conscious
- complex partial seizures – the person does not seem to be aware of their surroundings during the seizure and afterwards cannot remember what happened
- focal seizures – the person momentarily experiences symptoms of abnormal nerve function such as twitching, numbness, a feeling of déjà vu or unusual smells. A focal seizure can turn into a generalised seizure.
- generalised seizures – the person loses consciousness and may have muscle twitches, shaking, or violent movement of their arms and legs.

Seizures may be due to the tumour itself or due to surgery. For some people with brain tumours, seizures are their main disability or only symptom.

When someone has repeated seizures over time (due to any cause, including a brain tumour), the condition is called epilepsy.

Confirming the diagnosis

Not all episodes of abnormal brain function in people with gliomas are seizures. To diagnose a seizure, doctors need information about what the person experienced, and what was seen by anyone who was with them at the time.

The doctor may also order an electroencephalogram (EEG). Sometimes EEG can confirm that the episode was a seizure. However, people with brain tumours can have abnormal EEG readings even if they have not had seizures. Sometimes a seizure may not be detectable on the EEG.

Anticonvulsant medicines

Starting anticonvulsant medicines

Treatment with an anticonvulsant medicine should be started after the first seizure in a person with a brain tumour.

Starting anticonvulsant treatment before a person has a seizure is not recommended, because the benefits are unlikely to outweigh the risks of side effects.

Some anticonvulsant medicines can cause skin rashes (see *Skin problems*, later in this chapter).

Can seizures be controlled?

Anticonvulsant medicines can control seizures completely in about 60–70% of people with focal seizures, which are the more difficult type to control.

There are many different anticonvulsant medicines. If the first medicine or dose does not control seizures, doctors can try several options.

Taking anticonvulsant medicines with other medicines

Some anticonvulsant medicines, such as carbamazepine (Tegretol) and phenytoin (Dilantin), can reduce the effectiveness of other medicines, such as corticosteroids (e.g. dexamethasone), warfarin, oral contraceptives and some chemotherapy drugs. The dose of other medicines may have to be increased to offset this problem.

Some antibiotics can make carbamazepine remain in the body for longer, making it more toxic and causing more side effects.

Valproic acid (Epilim) may interfere with the way some chemotherapy drugs work, making them less effective as cancer treatment.

Some newer anticonvulsant medicines, such as gabapentin (Neurontin), levetiracetam (Keppra), and pregabalin (Lyrica), do not cause these problems when taken with other medicines.

Stopping anticonvulsant medicines

If a person taking anticonvulsant medicines has no seizures for a long time, it may be possible to gradually reduce the medicine over two-to-three months under medical supervision, then stop.

It is not possible to tell whether the seizures have stopped because the anticonvulsant is controlling them, or because the tumour or treatment is no longer causing seizures. The only way to find out is to stop taking the anticonvulsant medicine and see whether seizures start again.

When deciding whether to try stopping the anticonvulsant medicine, doctors will take into account all the factors affecting the individual person, such as:

- how severe their seizures were
- whether they have side effects from the anticonvulsant medicine
- whether they currently drive a car (In Australia, a person must stop driving while the anticonvulsant dose is reduced and cannot start driving again until at least three months after stopping the medicine.)
- how more seizures will affect the person's life
- the person's preferences.

In a person with a high risk of having more seizures because they have a high-grade tumour, the risk of more seizures usually outweighs any possible benefits of stopping the anticonvulsant medicine.

If the person and their doctors decide to stop an anticonvulsant medicine, it should not be stopped suddenly, but the dose should be gradually reduced over two-to-three months.

Surgery and radiotherapy

If seizures are significantly disrupting a person's life, surgery or radiotherapy may help control them.

Surgery to remove more tumour should be considered if a person has seizures that are not controlled by anticonvulsant medicines and the seizures are significantly affecting their quality of life. Surgery is only possible if the tumour can be removed without an unacceptably high risk of causing more brain damage.

Counselling for people with seizures

When a person with a brain tumour has experienced a seizure, their doctors or other health professionals should advise them and their families or carers about first aid for seizures, driving restrictions, how to avoid seizures, and the probability that their seizures will be successfully controlled.

Safety and first aid

People who have had seizures need information about how to minimise the dangers of having another seizure at home (e.g. drowning in the bath, burns from heaters or injury from

appliances), at work (e.g. falling, injury from machinery or vehicles), or during at leisure activities.

People at risk of seizures should try to avoid things that trigger seizures, such as:

- lack of sleep
- excessive alcohol
- illicit recreational drugs
- some non-prescription medicines (The person's doctor or pharmacist should provide information about these)
- other medicines that can make anticonvulsant medicines less effective (see *Taking anticonvulsant medicines with other medicines*, earlier in this chapter)
- suddenly stopping anticonvulsant medicine or missing doses.

The person's family and friends need to know what to do during a seizure and when to call an ambulance (Table 11.1). They should ask their doctor or contact person in the treatment team for instructions and written information.

Table 11.1 When to call an ambulance for a person with seizures

Someone should call an ambulance for a person with a brain tumour who has seizures if:

- the person has not had a seizure before
- the person is injured during a seizure
- a seizure lasts more than 5 minutes
- a second seizure starts before the person has completely recovered from a seizure
- the person has repeated generalised seizures occur within a 24-hour period
- the person is not awake and aware of their surroundings within 10 minutes of having a seizure.

Driving

If it not safe to drive a vehicle if there is a chance of having another seizure. There are national standards for drivers with epilepsy (recurring seizures), which apply in every state and territory and are enforceable by law. These standards include rules about what the person must do, including the following:

- When someone is diagnosed with epilepsy or has a seizure, they must contact the road transport authority in their state or territory and tell them they have had a seizure. They must provide medical reports to keep their license. Doctors must notify the authorities if they suspect that a person is driving or is not taking their anticonvulsant medicine.
- If a person has a seizure for the first time, they must stop driving immediately. If they have no seizure for the next six months, they are allowed to start driving again.
- If someone is diagnosed with epilepsy and starts anticonvulsant treatment, they must not drive for six months. If they have no seizure for the next six months and there is no

evidence that their brain tumour is growing or changing (e.g. from brain scans or symptoms), they are allowed to start driving again.

- If someone is stopping anticonvulsant treatment because they have not had a seizure for a long time, they must stop driving while the dose of their anticonvulsant medicine is reduced and cannot start driving again until at least three months after stopping the medicine.

There is information about driving in **Chapter 13. Rehabilitation**.

More information

A brochure about brain tumours and driving (*Brain tumours and driving. A guide for patients and carers*) is available from The Cancer Institute NSW (www.cancerinstitute.org.au), Cancer Council Australia (www.cancercouncil.org.au) or the Cancer Council helpline 13 11 20.

Brain tumour support groups can be very helpful in providing information, practical advice and emotional and social support for people with seizures.

More information about driving restrictions for people with seizures is available from:

- Epilepsy Action Australia (<http://www.epilepsy.org.au/driving.asp>)
- Licensing authorities in each state or territory:
 - ACT – Australian Capital Territory Road Transport Authority
 - NSW – Roads and Traffic Authority, New South Wales Government
 - NT – Motor Vehicle Registry, Northern Territory Government
 - Qld – Queensland Government Department of Transport and Main Roads
 - SA – Motoring, Government of South Australia Department for Transport, Energy and Infrastructure
 - Tas – Transport, Tasmanian Government Department of Infrastructure, Energy and Resources.
 - Vic – Vicroads, State Government of Victoria
 - WA – Licensing services, Government Western Australia Department of Transport.

Skin problems

People with gliomas can experience a range of skin problems caused by the tumour or treatments.

Side effects of medicines

Some medicines can cause reactions in the skin, such as rashes. These can be caused by hypersensitivity (allergy-like reaction to an ingredient in the medicine), or by toxic effects of medicines due to problems with the liver or kidneys.

A skin reaction caused by hypersensitivity is usually a rash of red spots, which turn white when pressed, and may or may not be itchy.

Skin reactions can sometimes be a sign of a serious medical problem. Even a mild skin rash could indicate that the medicine is severely toxic for the individual.

To work out which medicine is causing a skin rash and why, doctors may need to get the person to stop taking one or more medicines to see if the rash goes away, and then start again.

If doctors suspect that the problem could be serious or life-threatening, the person may have to stop all medicines that could be possible causes to reduce the risk of death.

Skin rashes and anticonvulsant medicines

Anticonvulsant medicines have a higher risk for serious reactions than most other medicines commonly taken by people with brain tumours. If a rash occurs in a person taking anticonvulsant medicine, they should tell their doctor immediately.

However, rashes are very common, and can also be due to other causes that are not serious. Some rashes will disappear without treatment.

If a rash occurs during the first five days of taking an anticonvulsant medicine, it is usually not due to the medicine.

If a rash occurs during the first few months of taking an anticonvulsant medicine (especially with phenytoin, carbamazepine, phenobarbitone and lamotrigine), doctors will normally do blood tests to check how well the person's liver and kidneys are working (liver function tests and renal function tests).

In a person who has already been taking an anticonvulsant medicine for some time, a rash may begin when dexamethasone reduced or stopped.

Skin problems caused by radiotherapy

Radiotherapy can damage skin as well as killing the tumour, because it targets cells that grow and divide rapidly. The risk of skin damage is minimised by dividing the total dose of radiation into many smaller doses or changing the position.

Most skin problems caused by radiotherapy begin within days to weeks as a faint pinkness, then the area becomes redder.

These short-term radiation skin reactions (sometimes called radiation dermatitis) can be relieved by applying a moisturiser. Mild skin reactions will usually be relieved by a non-irritant moisturiser without fragrance, such as sorbelene. If the skin is itchy, the person may need a mild corticosteroid cream such as 1% hydrocortisone cream.

Some people develop skin ulcers after radiotherapy. These usually heal without treatment, but can recur if the dose is high. If the skin is itchy, slightly dented or weeping clear fluid, it may be helpful to use:

- creams and cleansers that contain oatmeal
- wet compresses with a cool, slightly damp cotton towel or wrap for 30–60 minutes one-to-three times per day.
- mild- to moderate-strength topical corticosteroid cream very sparingly for a few days at a time, together with a moisturising cream.

Radiation dermatitis usually disappears over weeks to months. Afterwards the person may have darker skin in that area for a while.

After high doses of radiation, an area of skin will usually become hairless, drier and more sensitive. People who receive doses of more than 45 Gy^{xxiii} will usually have permanent hair thinning or hairlessness in the area. Hair transplant is possible if the skin is healthy enough. Several years after radiotherapy the area of skin often becomes thinner, dryer and semi-translucent so that blood vessels can be seen through the skin.

People who have had radiotherapy must protect the area of skin from sunlight, because these areas have a higher risk for skin cancer.

Blood clots (venous thromboembolism)

Venous thromboembolism is the medical term for the formation of a blood clot in a major vein in the legs (deep vein thrombosis [DVT]) or lungs (pulmonary embolism). It is common in people who are immobile for a long period, hospitalised patients, and people recovering from surgery or serious illness including brain tumours.

About one in 20 (5%) people who have brain surgery develops a blood clot in the lung and about 20–40% develop a blood clot in the legs.

People with brain tumours have a higher risk of blood clots if they:

- have weak legs
- have a diagnosis of glioblastoma multiforme
- are over 60 years old
- have a large tumour
- have had chemotherapy
- have had surgery lasting more than 4 hours.

Venous thromboembolism causes death in fewer than one in 100 cases, but it can cause serious complications. About one in three (30%) people who recover from DVT later develop symptoms of long-term problems with the veins in their legs (postphlebitic syndrome).

Prevention

Blood clots can be prevented by special compression stockings and anti-clotting medicines such as heparin.

Preventive treatment with heparin (usually given by injection under the skin) is recommended for most people with a glioma, especially those most at risk because they are elderly, unable to walk much, or have a high-grade tumour.

These medicines can increase the risk of bleeding, so they should be stopped if the person needs surgery. Treatment should be started again after surgery and continued until the person is active and walking again.

^{xxiii} The standard unit for measuring radiation is the Gray (abbreviated as Gy).

While in hospital:

- Patients who have brain surgery should have a compression pump machine used on their legs while in hospital, until they are walking again.
- Injections to prevent clots are used in some patients who are not at high risk of bleeding after brain surgery. Heparin treatment might not be given if the risk of bleeding is too high.
- Patients may be given compression stockings to wear after surgery.

Treatment for blood clots

Treatment with heparin is recommended to treat blood clots in people with gliomas. Some people may also need to take warfarin tablets afterwards. The length of warfarin treatment depends on the individual's level of risk.

If a blood clot occurs immediately after brain surgery, heparin and warfarin are not normally used and the clot is treated other ways.

Bleeding is a serious side effect of warfarin. About one in 400 people taking warfarin (0.25%) experiences life-threatening bleeding each year. The risk is higher for people with risk factors, including old age and brain tumours. Brain tumours could have a higher risk of bleeding into the brain, because they have a more blood vessels than normal brain tissue.

Swelling in the brain (oedema)

Oedema is common in people with brain tumours and leads to symptoms of headache, nausea and vomiting. Oedema can be seen on brain scans. (There is more information about headaches in **Chapter 4. Symptoms of brain tumours.**)

Treatment with dexamethasone is recommended for people oedema in the brain who have oedema seen on brain scans and also have symptoms. It is not normally given if the oedema is seen on a scan but the person has no symptoms.

Dexamethasone is also used to help prevent oedema in people who have radiotherapy to a large part of the brain.

The usual starting dose of dexamethasone is 16 mg each day, usually given in two or four doses. If necessary, the total dose can be increased to 100 mg per day. Lower doses can also be effective, such as 4–8 mg per day for treating oedema, or 2 mg per day for preventing oedema caused by radiotherapy.

After starting dexamethasone, the dose should be gradually reduced until the person is taking the lowest amount that will still control their symptoms.

If possible, dexamethasone treatment should be gradually stopped after the person has finished radiotherapy. Dexamethasone treatment should not be stopped suddenly.

Dexamethasone and other corticosteroids can cause significant side effects. There is information about side effects of corticosteroids in the next section (*Other side effects of cancer treatments*).

Other side effects of cancer treatments

Radiotherapy

Although radiotherapy is aimed at the tumour, it damages surrounding healthy tissue as well.

Effects on brain function

The side effects of radiotherapy depend on a person's age, the doses of radiation given at each time, the total dose of radiation they received, and the timing of chemotherapy (if given).

Radiotherapy may increase a person's risk of having problems in ability to think, remember, solve problems and reason (cognitive function), especially problems with memory. However, the risk of developing memory problems is higher for people who have higher-than-recommended daily doses of radiation.

Brain tumours can cause the same problems, so it is not possible to be sure when radiotherapy is the cause. There is not yet enough evidence to know what side effects might show up in people who survive more than five years after radiotherapy.

Radiation dermatitis

There is information about the managing radiation damage to the skin in the section on skin problems.

Corticosteroids

Corticosteroids such as dexamethasone are commonly used by people with brain tumours to reduce swelling in the brain that is caused by leaky blood vessels (oedema).

These medicines have significant side effects. Patients and their relatives should be provided with written guidance about the corticosteroid dose and potential side effects. Common side effects include:

- high blood glucose (diabetes) in approximately half of patients treated with corticosteroids over a prolonged period
- high blood pressure
- muscle weakness (myopathy), especially in the shoulders and hips
- thinning of bones (osteoporosis)
- stomach ulcers (risk is low unless the person is taking other medicines as well)
- skin problems (thinning, bruising easily, stretch marks, acne, problems with wound healing)
- infections
- weight gain
- sleep disturbances
- mood changes

- psychological disturbance (restlessness, agitation, anxiety, behaviour change, or even psychiatric illness)
- change in body shape (round face, bump on back of neck)
- swelling of the feet
- indigestion.

These side effects can be reversed when dexamethasone is stopped.

Before starting, the person's weight, arm and leg strength, and blood glucose should be checked, and rechecked during treatment.

Osteoporosis is a major risk for people taking dexamethasone because it increases the risk of fractures, especially when taken long term and at high doses. The risk is also higher for older people, thin people, postmenopausal women and people with a history of fractures. A postmenopausal woman taking dexamethasone has a fracture risk three times higher than she would if not taking this medicine, regardless of her bone density when beginning treatment.

Prevention

Some side effects can be prevented in patients taking dexamethasone.

Treatment with a proton pump inhibitor medicine should be given to prevent stomach ulcers and bleeding inside the stomach if the person is also taking medicine to prevent blood clots or has had a stomach ulcer in the past. The risk is higher if the person is also taking a nonsteroidal anti-inflammatory drug (NSAID). Common over-the-counter NSAID-type medicines include aspirin, celecoxib (Celebrex), diclofenac (Voltaren), ibuprofen (Brufen, Nurofen), naproxen (Naprogesic, Naprosyn), but there are many different brand names. Patients should talk to their doctor or pharmacist about possible unwanted effects before buying any over-the-counter medicines for pain relief.

The most effective treatments to prevent bone thinning and fractures are bisphosphonate medicines such as alendronate (Fosamax, Alendro, Alendrobell, Adronat, Ossmax), etidronate (Didronel) or zoledronic acid (Aclasta, Zometa). Calcium supplements, vitamin D and calcitonin are also used. All postmenopausal women with brain tumours who are taking dexamethasone should be treated with one of these medicines unless their life expectancy is very short. Men and premenopausal women should have their bone density measured before starting dexamethasone, and treatment with a bisphosphonate may be needed if they are found to have thin bones.

Regular exercise may reduce the risk of muscle weakness.

Infections

Fungal infections caused by *Candida* species ('thrush') are common in people taking dexamethasone.

Patients with brain tumours receiving dexamethasone may have an increased risk of pneumonia caused by fungal infections with *Pneumocystis* species. Antibiotics to prevent *Pneumocystis* pneumonia may be given to patients receiving dexamethasone, radiotherapy and temozolomide chemotherapy at the same time.

Other medicines

All medicines can have side effects. Patients should make sure their doctor and pharmacist know all the medicines they are taking at any time, including non-prescription medicines or complementary medicines.

Interactions between medicines

A person with an astrocytoma or oligodendroglioma may have several medical problems that are due to the tumour itself or treatments.

Most people with brain tumours are taking several different medicines. Some combinations of medicines can have unwanted effects. For example, taking one medicine may worsen the side effects or toxicity of another medicine (see *Taking anticonvulsant medicines with other medicines*, earlier in this chapter).

It is important for the person's pharmacist and doctors to know all the medicines a person is taking, including any non-prescription medicines or complementary medicines.

Chemotherapy

Chemotherapy has side effects, because it can damage healthy tissue as well as the tumour. Common side effects of chemotherapy include nausea and vomiting, loss of appetite, tiredness and lack of energy, and infections. These problems can be managed effectively.

More information

A booklet about chemotherapy (*Understanding chemotherapy. A guide for people with cancer, their families and friends*), is available from www.cancercouncil.com.au or Cancer Council Helpline 13 11 20.

12. Psychological and social issues for people with brain tumours

Key points

Distressing physical problems

- Physical problems can be very distressing for a person with a brain tumour and for their family or carers.
- Doctors and other health professionals caring for a person with a brain tumour should listen to their concerns about physical problems, discuss problems and help them adjust to living with disabilities.

Changes in personality

- It is common for a person with a brain tumour to change their behaviour and personality. These changes can be subtle, or so obvious that family and friends might feel that the person is no longer their old familiar self.
- If a carer is concerned about personality changes, he or she should tell the person's doctor. The doctor can provide information and put them in touch with people who can help.
- A social worker, psychologist or psychiatrist can help carers understand the person's behaviour better and learn the best ways to respond to difficult behaviour.

Access to services

- Cancer care coordinators can help patients, carers and families to find the services and support they need. They can be contacted through the local health service caring for the person with cancer.

Problems with thinking (cognitive impairment)

- Changes in ability to think, remember, solve problems, reason and make decisions (cognitive function) are common in people with brain tumours.
- Problems with cognitive function may only be noticed by the person's family and friends. People with brain tumours will not usually express concern about problems with their thinking themselves. Changes in thinking might not be obvious to health professionals during medical consultations.
- If family or carers are concerned about the person's cognitive function, they should mention their concerns to the person's doctor.
- A neuropsychologist can test the person's cognitive function and identify their problem areas. Sometimes they may be able to find ways to help the person adjust to changes in their ability to think. Systematic testing, conducted in a standardised way, can also be useful when making decisions about the person's ability to go back to work or recommence other activities.

Anxiety, depression and other problems with mental health

- Anxiety, depression and delirium are common in people with brain tumours. These conditions can be treated effectively.
- If a person with a brain tumour is feeling distressed, they should talk to their doctors so that the best possible treatment can be given.
- If family or carers notice a sudden change in the person's behaviour, mood, conversation or thinking ability, they should tell the person's doctors.
- Doctors should assess these problems so that they can provide or arrange effective treatment.

Getting reliable information and planning for the future

- People with brain tumours and their families should expect doctors to provide information to help the person make decisions about their treatment. Health professionals and families should recognise that the person's ability to make decisions may change over time.
- While the person is still well enough to make decisions, they should think about planning for the future by making a will or writing down their wishes about the treatment they would like to be given if a time comes when they can no longer make their own decisions. This type of planning can help reduce uncertainty and distress for families if the person's tumour worsens suddenly and they become disabled.
- Doctors who treat people with brain tumours will normally be aware of who is legally allowed to make treatment decisions for the person when they are not capable of making their own decisions.

Quality of life concerns

- People with brain tumours should tell their doctors about any problems that are reducing their quality of life, even if the problem seems small.
- Health professionals should listen to the person's concerns about quality of life, take them seriously, and help if they can. A range of treatments are available to help people cope with brain tumours.

Treatments that help people cope

- Talking about things generally helps.
- Effective treatments can be provided by general practitioners, social workers, psychologists, psychiatrists or specially trained oncology nurses.
- People with brain tumours should ask for help when they are having trouble coping. Health professionals may not offer help unless asked, so patients and their families and carers should ask about what help is available.

Background

The diagnosis of any cancer is emotionally and psychologically difficult for patients and their families and carers. Malignant brain tumours are especially distressing, because we think of our brains as being very closely connected with our sense of self.

The diagnosis of any serious illness brings distress and uncertainty. For a person who has been diagnosed with a brain tumour – and for their family and friends – there are complex and difficult challenges.

Many people have not had any experience with cancer before they find out that they have a brain tumour. They may feel alone and afraid.

This chapter discusses some common issues that affect people with brain tumours and their families and friends. It sets out some of the things that help people cope with these problems.

Distressing physical problems

Physical problems caused by the brain tumour or its treatment are distressing, even when they are not life-threatening. Common problems include seizures, weight gain and other changes in physical appearance.

Seizures

Seizures are distressing for the person and for other people watching.

People who have seizures are not allowed to drive, according to national guidelines that are applied in every state and territory of Australia. (There is more information about driving in **Chapter 11. Managing symptoms and complications** and **Chapter 13. Rehabilitation**.)

Compared with the risk of dying, being unable to drive may seem trivial, but it is a mistake to assume that the person who is unable to drive will shrug it off. Being unable to drive can be very upsetting for the person, because it makes them less independent. The person may feel that their freedom, rights, social life and ability to participate in the workforce have been taken away. It is just one more reminder of the way life has changed, and leads to changes in relationships. The person might feel guilty that their family members and friends must drive them, or might feel resentful.

Changes in body appearance

Everyday living can be affected by weight gain due to treatment with steroids, weakness in the muscles of the face or limbs, or hair loss due to radiotherapy. As well as affecting the person's social life, these changes are very visible reminders of the serious health problems the person is facing. (There is more information about side effects of medicines in **Chapter 11. Managing symptoms and complications**.)

Changes in personality

Brain tumours can cause major changes in a person's behaviour and personality. Sometimes the family members are aware of slight personality changes before the tumour is even diagnosed. The person may not be aware that they are acting differently.

Common changes in personality in people with brain tumours include:

- becoming less flexible in their thinking
- becoming angry more easily
- being less sensitive to other people's problems
- poor judgement in behaviour or when making decisions.

The changes depend on which part of the brain the tumour is in. As well as the tumour itself, the person's behaviour and personality can be affected by surgery, radiotherapy, chemotherapy and some medicines such as corticosteroids.

Sometimes these problems settle down a little over time. This can happen because treatment has reduced the swelling inside the brain, the person has adjusted to corticosteroid treatment, or doses have been reduced.

There are no tests that can confirm personality changes, and the person is often unaware that they are behaving differently or that their behaviour is a problem. Family and carers sometimes feel that they are struggling alone, and can even begin to wonder whether they are overestimating the problem.

The person with the tumour may look completely normal, so other people in the community will not realise that their behaviour is caused by a brain tumour. This can result in difficult social situations.

Personality changes may also make it harder for the person to participate in social activities, so they become isolated. Carers can also feel 'trapped' and isolated from normal social life when caring for a person who can no longer enjoy the things they used to do.

Information about dealing with challenging behaviour is available from Cancer Institute New South Wales (http://www.cancerinstitute.org.au/cancer_inst/patients/).

Problems with thinking (cognitive impairment)

Brain tumours can affect a person's ability to think, remember, solve problems and reason (cognitive function). These changes may be so mild they are hardly noticeable, or may cause major problems.

Problems with mental tasks can be caused by the tumour blocking nerve pathways through the brain, or changes in brain chemicals. The type and severity of these problems can depend on:

- the location of the tumour within the brain
- the person's age (older people have more difficulties)
- treatments.

The person may not be aware that their thinking ability is impaired. They may not complain about it, and may even disagree with family members or friends who try to point out the problem. This can be a very distressing situation.

One type of cognitive function that is commonly impaired in people with brain tumours is 'executive function' – the set of skills necessary to make decisions and 'multi-task'. Normal executive function involves ability to self-monitor and self-correct, ability to think flexibly and change the pattern of thinking when necessary, ability to process new information, ability to organise, and ability to control urges such as anger and aggression. When someone cannot

do these things easily, they are unable to respond normally when faced with everyday decisions and can become very disabled. This problem can be a significant burden for family and carers, who may feel that they are struggling with the person to achieve everyday small tasks. The fact that the affected person ‘doesn’t get it’ makes the problem even more difficult.

Anxiety, depression and other problems with mental health

Anxiety and depression are common among people with brain tumours, but they are not always diagnosed by doctors treating the tumour. This may be partly because health professionals assume that a certain level of distress is ‘normal’ for a person facing such a difficult situation. It is important to identify anxiety or depression in a person with a brain tumour, because these conditions can be treated.

Anxiety

Anxiety is a feeling of being churned up and worried. A person with anxiety needs treatment if it is severe and distressing, or is causing problems with relationships, making treatment decisions, or participating in treatment (for example, being able to have radiotherapy).

Effective treatments for anxiety include medicines, relaxation therapy and guided imagery (a psychological technique that involves using the imagination).

Depression

A person with depression feels down, sad or overwhelmed for most of the time over a long period (more than two weeks at a time). Depression is not the same as feeling sad and distressed about a difficult diagnosis. People who are depressed feel helpless or without hope, cannot enjoy things, or may even feel guilty or a burden on others.

Depression can be a side effect of treatment.

Research suggests that people with brain tumours are more likely to become depressed if they are younger (under 55 years), have less support from other people or live alone, have children under 21 years, have economic problems, have relationship problems or stressful life events, have had mental health problems or problems with alcohol or substance use in the past.

Depression can be effectively treated. Sometimes this will include medication, but not always. Before prescribing any medicines for depression, the doctor must carefully consider any possible interactions with other medicines that the person is already taking. Talking therapies and techniques that help with negative or painful thoughts can be particularly helpful.

More information

A fact sheet about depression in people with brain tumours (*Brain tumours, depression and anxiety disorders*), written by Brain Tumour Alliance Australia and beyondblue, the national depression initiative, is available from beyondblue (1300 22 46 36 or www.beyondblue.org.au).

Delirium

Delirium is a condition in which a person is confused. Often the person sleeps poorly at night or is restless and has vivid dreams, and sleeps during the day. Sometimes a person with delirium will describe feelings of agitation, and report seeing odd objects, or hearing unusual sounds (hallucinations).

Delirium can be caused by medical problems, including medicines such as corticosteroids, which affect the brain's ability to function normally.

Because delirium tends to fluctuate during the day, it may not be diagnosed by the person's doctors and treated. Often it is family members who notice a sudden change in the person's behaviour, mood or ability to concentrate on something or participate in a conversation.

If a person with a brain tumour is acting in a way that suggests they could have delirium, it is very important for them to have a complete examination and tests to find the cause so they can be treated. Medicines are usually needed to help the person feel calmer and less distressed, and improve their ability to think.

Getting reliable information and planning for the future

Making decisions about treatment

It is the responsibility of the doctor treating the person to provide reliable information to help them make well-informed decisions about their treatment. Information should include:

- facts about the type of tumour they have
- which treatments are available, including alternative options
- what each treatment option can be expected to achieve
- the likely effects of having no treatment or delaying treatment.

Sometimes the person with a brain tumour may find it hard to understand or process this information, and may not be able to make decisions properly.

Legislation about who can make decisions on behalf of another person differs between states and territories. The hospital social worker who is part of the multidisciplinary team will be able to provide more information. In most states and territories a carer (the person's spouse, a near relative, a close friend or the primary carer) is legally allowed to make decisions about the person's treatment. In most cases, there is a clear set of steps to work out who can make decisions for the person. In some situations, a guardian is appointed by the guardianship board in that state or territory, to make treatment decisions.

Planning for the future

Although it is very confronting to think about end-of-life issues, making definite plans for the future can help the person's family and friends respect their wishes.

Most states and territories have legislation that enables a person to record their wishes about what treatment they would like if they later become too ill to make their own decisions (these agreements are called ‘advance care directives’).

Making a will is another important practical issue to attend to while the person is well enough. If a person with a brain tumour becomes very unwell suddenly and they have not made a will, the situation for their family can be much more distressing and complicated. (There is more information about planning for end of life in **Chapter 15. Palliative care.**)

Quality of life concerns

Quality of life is very personal. Each person’s own idea of what makes living worthwhile should be respected.

A person with a brain tumour should not feel that their concerns are minor or that they don’t have a right to be upset by things that affect their quality of life. People living with brain tumours should discuss their concerns with the health professionals who are treating them.

When a person with a brain tumour has personality changes or problems with cognitive function, their family and friends can experience worse quality of life as well as the person. Research has shown that these problems are even more difficult for a person’s family than coping with a physical disability.

Treatments that help people cope

Effective treatments or ways of coping can help in many situations. These include cognitive–behavioural therapy (CBT), supportive psychotherapy and group support.

Cognitive–behavioural therapy

Cognitive–behavioural therapy (usually called CBT for short) is a type of psychological treatment given by a trained health professional, usually a psychologist. It involves helping the person identify unhelpful thought patterns and changing them to more helpful thought habits.

For example, over time a person with a brain tumour might have gotten in to the habit of thinking “I’m useless because I can’t drive and my family is sick of me”. The psychologist might help the person explore their evidence for this belief and find evidence that they are not useless (e.g. tasks they still perform, positive aspects of relationships), and explore evidence for ways that family members are coping. The person is trained in getting into the habit of more realistic and positive beliefs.

Cognitive–behavioural therapy can include relaxation therapy, which can be very powerful in helping to reduce anxiety and distress.

Supportive psychotherapy

Many people with brain tumours describe feeling anxious about the future, feelings of guilt about what might have caused the brain tumour, or fear that their family will not cope. They often feel that they cannot tell their family about these feelings without causing more suffering.

Research has shown that people with all types of cancer feel less distressed if they are able to talk to another person, share experiences and just ‘tell it like it is’. Many find that being able to talk about these worries without upsetting the other person, and being listened to without feeling judged, can feel like a ‘weight off their shoulders’.

This kind of therapy can be provided by psychologists, psychiatrists, general practitioners, social workers, or by specially trained nurses in some cancer clinics.

Sometimes the therapist will also arrange to talk to family members, to help improve communication and overcome the feeling that everyone is ‘walking on eggshells’ when dealing with the person with the brain tumour.

Group support

Hearing about other people who have had a brain tumour and sharing tips for coping can be enormously reassuring. Attending a support group or participating in an online community can make people feel that they have been heard and that their experience is validated. People also benefit from feeling that they are contributing something to the group and are helping other people.

However, not everyone likes to talk in a group setting. For some people it can be very confronting to see people become unwell and think “that could be me”. The choice to meet other people with cancer should be up to the person and depends on their own preferences. The latest evidence does not show that people with cancer live longer if they participate in group support.

Organisations that can help

Brain Tumour Alliance Australia (1800 857 221 or www.btaa.org.au) provides peer support for people with brain tumours and their families.

beyondblue (1300 22 46 36 or www.beyondblue.org.au) provides information and support for people with depression and anxiety.

The Cancer Council Australia (www.cancer.org.au) provides information for people with cancer and their families and carers.

The Cancer Institute NSW (www.cancerinstitute.org.au) provides information for people with cancer and their families and carers.

13. Rehabilitation

Key points

- After treatment for a glioma, a patient whose medical condition is stable should be referred to a rehabilitation service if they have ongoing problems affecting everyday life.
- People who expect to start driving again after treatment for a brain tumour should be referred to a rehabilitation service for full assessment of their ability to drive safely.

Background

People with brain tumours commonly experience problems with physical function and quality of life. Common problems include:

- difficulty with memory and thinking (about 80%)
- weakness (78%)
- problems with seeing and perception (53%)
- numbness or other sensory loss (38%)
- bowel and bladder dysfunction (37%).

Rehabilitation services provide assessment and treatment by a range of medical, nursing and allied health professionals with special expertise, including:

- rehabilitation physicians (medical specialists who specialise in rehabilitation medicine)
- physiotherapists
- occupational therapists
- social workers
- speech pathologists
- clinical psychologists and neuropsychologists.

After treatment for a glioma, a patient whose medical condition is stable should be referred to a rehabilitation service if they have ongoing problems affecting everyday life.

Aims of rehabilitation

Rehabilitation therapy can help a person enjoy their life more and participate better in social life:

- Physiotherapists mainly focus on improving a person's movement, strength, coordination, balance and ability to walk.
- Occupational therapists focus on improving the person's ability to carry out everyday tasks (usually called activities of daily living) and become as independent as possible.

Occupational therapists assess the person's home or care environment as well as their physical abilities and find ways to make living easier.

- Social workers aim to improve the person's social situation and can arrange access to government services such as Centrelink.
- Speech pathologists provide assessment and treatment to help a person who has problems with swallowing, communication and verbal interaction.
- Clinical psychologists and neuropsychologists, where available, should also provide assessment and therapy for people who have problems with memory, thinking and reasoning, or with anxiety and depression.

There is increasing evidence that for people with brain tumours who have symptoms of abnormal brain function, such as muscle weakness, rehabilitation in the earlier phases of their disease is as effective as it is for patients after a stroke or accidental brain injury.

Driving

People who expect to start driving again after treatment for a brain tumour should be referred to a rehabilitation service for full assessment of their ability to drive safely. The assessors will make a recommendation to the licensing authority in the person's state or territory, such as:

- the person is not safe to drive at all
- the person is safe to drive with some restrictions
- the person is safe to drive an adapted vehicle
- the person is safe to drive without any restriction.

A person would not be allowed to hold a commercial driver's licence or an unrestricted private driver's licence if they have any of these:

- malignant brain tumour
- damage to the part of the brain that processes information from the eyes (visual fields)
- double vision (diplopia)
- uncontrolled epilepsy
- impaired judgement.

The licensing authority will make a decision about whether the person is permitted to drive. The person must obey the determination of the driver licensing authority.

Most people with high-grade gliomas will not be permitted to drive. For those who can return to driving, regular ongoing follow-up by the rehabilitation service is needed, to review and manage any on-going risk associated with driving.

If someone continues to drive unsafely and disobeys any restrictions of the driver licensing authority, their license may be cancelled. In some states and territories, doctors may be legally responsible to notify the authorities.

14. Follow-up

Key points

- Follow-up visits are generally every one-to-three months for people with high-grade tumours and every three-to-six months for low-grade tumours.
- The whole treatment team should be available for follow-up visits, as needed.
- Follow-up involves adjusting medicines such as dexamethasone and anticonvulsant medicines.
- All patients should be assessed by a rehabilitation physician and occupational therapist before being certified as safe to drive.

Why, when and how often?

The aims of follow-up for people with brain tumours are:

- to keep checking how well the tumour is controlled
- to assess symptoms caused by the tumour or treatments, and manage any symptoms to minimise their effect on the person's life
- to provide psychological support.

There is no known ideal timing for follow-up visits. . The time between visits will differ between people and the treating team of health professionals should decide how often an individual needs to visit. Generally, a person should return for follow-up:

- every one-to-three months if they have a high-grade astrocytoma or are receiving chemotherapy
- every three-to-six months if they have a low-grade astrocytoma or oligodendroglioma.

Who should provide follow-up?

Coordinated care is now the standard approach for caring for people with brain tumours, because they have complex needs involving several different specialists.

Members of the multi-disciplinary team should be available at follow-up visits. The patient may need to be assessed or treated by the treating specialists (neurosurgeon, radiation oncologist and medical oncologist), neurologists, social workers, nurses, radiologists, physiotherapy, occupational therapy rehabilitation and palliative care specialists, and psychologists or psychiatrists as necessary.

The person's general practitioner (GP) will also be involved in caring for a person with a brain tumour, but would not normally provide the follow-up checks. Brain tumours are rare, so most GPs will not be experienced in their treatment.

The team should make sure the person knows which team member to contact at any time between visits. Having someone coordinate care between all the different providers is likely to make it easier for patients and their families to cope with follow-up.

Adjusting medicines

Dexamethasone

The dose of dexamethasone should be gradually reduced and stopped when possible. It should never be stopped suddenly, because severe sudden swelling (oedema) could occur in the brain.

Oedema can have the same symptoms and appearance on brain scans as a tumour that is growing and worsening, but the symptoms can be rapidly controlled by increasing the dose of dexamethasone.

If the dose is too low, it can take a week for oedema to develop, so doctors may need to keep checking the person and fine-tuning the dose of dexamethasone to keep symptoms under control.

While taking dexamethasone, patients need regular checkups to look for common side effects such as high blood glucose (diabetes), thinning of bones (osteoporosis), muscle weakness (myopathy) or stomach ulcers or damage to stomach lining. (There is more information about dexamethasone in **Chapter 11. Managing symptoms and complications.**)

Anticonvulsant medicines

Anticonvulsant medicines should only be stopped after consultation with a neurologist, if:

- the person has had no seizures for a long period
- the tumour is stable and not growing
- the electroencephalograph is normal.

Anticonvulsants should not be stopped suddenly because there is a risk of causing a seizure. (There is more information about anticonvulsant medicines in **Chapter 11. Managing symptoms and complications.**)

Assessing safety for driving

For people who have had seizures, follow-up visits may involve assessments that are required by licensing authorities in each state and territory before a person is allowed to drive a vehicle again.

All patients should be assessed by a rehabilitation physician and occupational therapist before being certified as safe to drive. Even if they seem fit to drive in a normal consultation, they may have brain changes that could make driving very unsafe. (There is more information about driving in **Chapter 13. Rehabilitation.**)

15. Palliative care

Key points

- Palliative care involves coordinated care from doctors, nurses and allied health professionals to improve the life of a person with a medical condition that will eventually end their life. It focuses on the whole person within their social and emotional context, not just the cancer.
- Palliative care improves patients' symptom control and general wellbeing, and can reduce the number of unnecessary tests a person undergoes.
- Palliative care can be given at home, or in a hospital, nursing home, palliative care unit or hospice.
- People with symptoms that are difficult to control, or who are having trouble coping, will benefit from the involvement of a specialist palliative care service earlier in their illness.
- All patients with advanced disease that will end their life should be given the opportunity to discuss prognosis and end-of-life issues before they are too ill to be involved in making decisions.
- Early in the illness, while the person is still able to think clearly and make decisions, health professionals should invite the person to discuss their wishes for the end of their life and make plans to ensure their wishes are carried out.
- Palliative care teams are expert in managing difficult symptoms in a person with a brain tumour, such as fatigue, headache, nausea and vomiting, and cognitive impairment.
- Special problems towards the end of life can include problems with feeding and swallowing, seizures, bowel and bladder problems, and pressure sores.
- The dose of corticosteroids needs to be adjusted closely at the end of life to maintain control of symptoms while avoiding side effects.
- The aim of palliative care when the person is in the last stage of dying is to provide good symptom control for the patient, support for their carers, and not to either deliberately speed up death or prolong it artificially.
- As death approaches, non-essential medicines should be stopped and all medicines essential for symptom control should be continued.
- Many people dying from brain tumours spend more and more time asleep and eventually go into a coma and die peacefully.

Background

Despite advances in the diagnosis and treatment of brain tumours, primary malignant brain tumours are usually not curable. Towards the end of life, patients can have significant symptoms and concerns, and family and carers may be under considerable stress.

Palliative care has an important role in caring for patients with brain tumours.

What is palliative care?

Palliative care is a coordinated approach to care provided by doctors, nurses and allied health professionals. The aim is to improve life as much as possible for a person who has a medical condition that will eventually end their life. It focuses on the whole person within their social and emotional context, not just the tumour.

Palliative care provides physical, psychological, emotional and spiritual support for patients and for patients' families and friends. It involves planning ahead to minimise distress, rather than just intervening when there is a crisis.

It can be given in hospital or other care institutions, or in the person's own home by a visiting team.

When palliative care professionals become involved in a person's care, this does not necessarily mean that cancer treatment, such as surgery, radiotherapy or chemotherapy will be stopped. The emphasis of care is changed to that of support and symptom control rather than cure. The care is often shared between the palliative care team and the person's original cancer doctor or surgeon.

As death approaches, the palliative care team takes a greater role, although the cancer doctors will usually maintain contact with the patient.

What can palliative care achieve?

Specialist palliative care services should be available for all patients who would benefit.

The involvement of a specialist palliative care team in the care of patients with cancer:

- improves the patient's symptom control and general wellbeing
- helps the patient and family come to terms with the changing emphasis of care
- reduces the number of unnecessary tests and investigations
- increases patients' and carers' satisfaction with the person's health care
- increases the amount of time patients can spend at home and reduces the time spent in hospital
- reduces the overall cost of care
- increases a person's chance of dying in a place they choose (e.g. at home).

Organising palliative care

Who arranges palliative care?

The person's main doctor or another member of the medical team arranges referral to palliative care. Most metropolitan hospitals have a palliative care team consisting of doctors, specialist nurses and allied health workers who can review patients in hospital.

Sometimes the person's GP will organise palliative care, and continue to be involved in caring for the person at home.

Palliative care at home

Where possible, care is delivered in the environment of the patient and carer's choice. This may be the place where the person is living, such as their own home, the home of a relative or carer, or a nursing home or hostel.

When palliative care is given in the person's home, it is given mainly by the person's general practitioner, with help from community teams. The local palliative care service will usually have specialist palliative care nurses and a specialist palliative care physician as well as counsellors, pastoral care workers and volunteers. Physiotherapy, nutritional support, occupational therapy and home help may also be available through other community services linked to the palliative care service.

Several studies have found that many patients say they would prefer to die at home. Carers and relatives of terminally ill patients need support when caring for patients at home, particularly for activities of daily living and domestic chores. This can be stressful and can cause more social disruption when compared to those patients who are cared for in institutions.

Hospitals

Patients being cared for at home or somewhere else may need to be admitted to a normal (acute) hospital, even if they are no longer receiving treatment for the cancer.

This may happen if the person has seizures that cannot be controlled, infections, or symptoms that are difficult to control, or if their carer can no longer cope with all the tasks required. People with brain tumours have often had frequent contact with hospital staff and feel safe and secure there.

Hospices and palliative care units

Admission to a specialist palliative care unit or hospice may be required so that new symptoms or problems can be properly assessed and medicines reviewed, or for care until the person's death.

Sometimes a person being treated for cancer in an acute hospital will be admitted directly to a hospice instead of going home. This may happen if the person has symptoms that need specialised skills to control, and going home is not feasible.

A family caring for a patient at home may need to organise temporary care by health professionals for many reasons. Services that provide temporary care for a seriously ill person when their usual carer needs a break are called respite care services. Respite care can be provided in the community, at home, in special palliative care facilities or hospices.

When should palliative care start?

Referral to palliative care should not be delayed until the last few months of life. People with symptoms that are difficult to control or who are having trouble coping will benefit from specialist palliative care service earlier in their illness.

Because the palliative approach pays attention to symptom control and the psychological, social and spiritual wellbeing of the patient and their family, it is helpful at all stages of the cancer, particularly at the end of life.

Incorporating palliative care into standard cancer care

It is easier to provide palliative care throughout the person's illness if the palliative care team is integrated into the medical team providing cancer treatment. Doctors should offer people with cancer referral to palliative care early in their illness so that the palliative care team can collaborate with the medical team. This can allow planning of future care according to the person's wishes and a smoother change from treatment that aims to prolong the person's life to treatment that aims to maximise their quality of life at the end of life. This approach avoids the need to make decisions during a crisis.

Specialist neuro-oncology nurses are now becoming involved in providing support for patients who have just been diagnosed with a brain tumour as well as those with advanced cancer.

Planning ahead

All patients with advanced disease that will end their life should be given the opportunity to discuss prognosis and end-of-life issues before they are too ill to be involved in making decisions. Most patients prefer to be given some information about prognosis when they are first diagnosed with a life-limiting illness. The amount of information given and the distress that this causes will vary from patient to patient. It is often very difficult to predict how long a patient has to live and many doctors speak generally in terms of weeks or months or years rather than specific dates.

Palliative care experts have developed checklists for patients with advanced cancer and their families or carers, to help them ask appropriate questions about what is likely to happen to the person in future and what to expect from treatment.

More information

A booklet containing helpful checklists (*Asking questions can help*)^{xxiv} is available from Palliative Care Australia (<http://www.palliativecare.org.au>).

Individuals prepare for death by completing any 'unfinished business', for example, signing a legal wills, contacting loved ones, or legally delegating the management of personal affairs to someone else. (There is more information about appointing someone else to make decisions in **Chapter 12. Psychological and social issues for people with brain tumours.**)

Early in the illness, while the person is still able to think clearly and make decisions, health professionals should invite the person to discuss their wishes for the end of their life and make plans to ensure their wishes are carried out. Formally recording the person's wishes in writing is called advanced care planning.

^{xxiv} Clayton J, Butow P, Tattersall, M. *Asking questions can help. An aid for people seeking the palliative care team.* Sydney: Medical Psychology Research Unit, The University of Sydney; 2002.

Issues to be discussed between the patient, their family and health care team include the person's wishes about resuscitation, tube feeding, antibiotics and intravenous fluids. The person should also be given the opportunity to say where they want to die and who should be present at the time of death. The majority of people prefer to die at home. In reality, only a minority of people die at home. This is partly because looking after a dying person is often more difficult than carers imagine, and towards the end they need professional help. A person is more likely to have their wish of dying at home if a community palliative care service is involved and there is strong family support.

Occasionally a dying person or their relatives or carers will ask for medical staff to help make death happen sooner. Patients who ask for euthanasia are often asking for an end of their suffering, rather than for an end of their life. Asking for help to die has also been linked to depression. Often the person does not ask again after distressing symptoms have been controlled.

Managing symptoms

Fatigue

Fatigue is a persistent sense of tiredness or exhaustion that is not due to activity and which is distressing and interferes with the person's normal life. Fatigue is the most common symptom experienced by patients with brain tumours.

It can be due to various medical causes including anaemia, uncontrolled pain, anxiety, depression, weight loss, infection, lack of sleep, side effects of medicines and loss of fitness from decreased physical activity.

Management of fatigue can involve treatment of a specific cause, such as a blood transfusion for anaemia or special pain management techniques for difficult-to-treat pain.

General management for fatigue can involve teaching the person ways to conserve their energy, tailored exercise programs, help with organising everyday activities, and psychological help such as stress management, relaxation techniques and support groups.

Headache

'Brain tumour headache' is usually caused by an increase in pressure on parts of the brain that are sensitive to pain as the tumour causes swelling inside the skull. Corticosteroids such as dexamethasone are used to reduce the swelling. (There is more information about managing headaches in **Chapter 11. Managing symptoms and complications.**)

Headaches caused by brain tumours are also treated with simple painkillers, such as paracetamol or non-prescription nonsteroidal anti-inflammatory drugs such as ibuprofen (brand names include Brufen and Nurofen). If simple painkillers do not stop the headache, stronger painkillers such as morphine and morphine-like drugs may be needed. If the person has significant side effects from dexamethasone, morphine should be started early instead of trying simple painkillers first.

If the person is unable to communicate, it may be difficult to tell whether they have a headache. Doctors and carers should look out for signs that the person is in pain, such as frowning or rubbing their head.

Nausea and vomiting

Brain tumours can cause nausea and vomiting directly, by triggering the part of the brain that controls vomiting. If doctors suspect that swelling inside the skull is causing the vomiting, the first treatment is usually dexamethasone.

If vomiting is difficult to control, mannitol is sometimes used by intravenous infusion. Mannitol acts as a diuretic (reduces fluid levels in the body to reduce the swelling in the brain).

Sometimes nausea has other causes, such as side effects of medicines or motion sickness. Anti-nausea medicines such as metoclopramide (brand name Maxolon) or prochlorperazine (brand name Stemetil) may be used.

Problems with thinking (cognitive impairment)

An inability to think clearly, understand things properly and make reliable decisions can interfere with work and relationships with family and carers, and can spoil the person's quality of life.

These problems can be due to the tumour or made worse by surgery chemotherapy and medicines such as dexamethasone, morphine-like drugs and anticonvulsant medicines.

The person's cognitive function should be carefully assessed at each visit, from the time of diagnosis onwards. This involves testing and asking questions about attention span, memory, ability to learn and process information, ability to do different tasks at the same time, mood and personality. (There is more information about problems with thinking in **Chapter 12.**

Psychological and social issues.)

Managing special problems at the end of life

Problems with feeding and swallowing

As a person approaches death, they will often lose their appetite, take very little by mouth and find it difficult to swallow. There may be a risk of food 'going down the wrong way' and causing pneumonia. This risk can be reduced by giving thickened fluids. During the final phase of life, a total inability to swallow is a normal phenomenon.

Problems with feeding can be very difficult for families and carers. It is important to understand that:

- artificial feeding by tubes does not prolong the life of a person who is already dying
- not wanting to eat anymore is a normal part of dying.

Fluids

Doctors do not completely agree about whether people with brain tumours should be given fluids by intravenous infusion (drip) at the very end of their life. There is a risk of causing more swelling in the brain and worsening symptoms. Most doctors agree that, in general, people in this situation would not benefit from being given fluids artificially, but that each case should be considered individually.

Whether or not a person is given fluids artificially, they should be given high-quality nursing care with attention to pain relief and symptom control, with meticulous attention to mouth care.

Seizures

The main difficulty in treating seizures at the end of life is how to give the medicine. As a person's health worsens, they become drowsy and are often unable to swallow. Anticonvulsant medicines cannot usually be given through a drip.

Some seizure medicines can be given as drops in the mouth, rectally, or by injection under the skin using a small, non-painful needle.

Bowel and bladder problems

Bowel management may be complicated by the patient's inability to move, weakness in the arms or legs, or inability to speak.

Carers need to be trained in the use of appropriate equipment, such as hoists and slings to move the person onto a commode or toilet.

People with brain tumours are at risk of constipation if they are mainly sitting or lying still and are not eating much. Constipation can be treated by laxatives, and by enemas or suppositories into the rectum.

Inability to control urination is also common and can be caused by many factors. The person may be unable to tell carers when they need to urinate, or may be unable to stop their bladder emptying. Urinary tract infections or diabetes caused by dexamethasone can make this problem worse.

Incontinence aids to make a person more comfortable and secure include panty liners, continence pads or continence pants. Catheterisation or condoms to collect urine are sometimes used.

People may need to urinate multiple times during the night and may accidentally urinate during their sleep, especially if they have memory problems, are paralysed, or need to urinate more often than normal. The need to get up during the night increases the person's risk of falls, and can stop the patient and their carers from getting enough sleep. This problem can be very difficult to manage. Sometimes respite care is needed.

Pressure sores

Almost all patients who cannot leave their bed will have skin problems caused by lying too long on one spot. These are often called 'pressure sores' or 'bed sores'.

The risk is high if the person cannot move or is inactive, has been treated with corticosteroids such as dexamethasone for a long time, and has dry skin that is damaged by rubbing on sheets or clothing when the person is moved by their carer.

Once a pressure sore has formed, they are very difficult to heal and can cause major problems for the person. If very severe, they can cause constant pain and can become infected.

Prevention of pressure sores is essential for a person who cannot leave bed. The risk can be reduced by:

- turning the person every two hours
- using sheepskin rugs
- resting the person's heels on water balloons (these can be made at home from rubber gloves).

Assessment by an occupational therapist should be arranged for people unable to move from bed. Special equipment may be needed to help the carer.

While a pressure sore is healing, the person may need an extra dose of painkillers before the dressing is changed each time. A person with pressure sores that are not healing may need specialised care from a wound care management nurse or stomal therapist. Many hospitals employ these specialist nurses.

Corticosteroids (steroids) at the end of life

Almost all patients with brain tumours will be treated with corticosteroid medicines such as dexamethasone. The main purpose is to reduce pressure in the brain, which can reduce headaches, nausea and vomiting and make the person more alert. Often a dose of dexamethasone will rapidly and substantially improve symptoms of problems with brain or nerve function.

Dexamethasone is often given to help the person's appetite, pain, breathing problems, mood and tiredness. It can be given by mouth or by injection, usually in the morning to try to avoid sleep disturbance.

Long-term use of corticosteroids has side effects. The benefits must be weighed up against the risk of side effects. The dose should always be kept to the lowest dose needed to control symptoms, and the person should be checked often for side effects. (There is more information about side effects of corticosteroids in **Chapter 11. Managing symptoms and complications.**)

These medicines can stop being effective over time. Doctors do not agree on whether corticosteroids should be used at the end of life. Many doctors stop the medicine when the person can no longer swallow tablets. Other doctors continue to give the medicine by injection. When the person is dying, continuing to give corticosteroids or increasing the dose could prolong their death and may not improve quality of life. Corticosteroids must not be stopped suddenly, but must be gradually reduced.

Care of the dying patient

Although focussing on quality of life, palliative care is also concerned with the quality of dying.

A 'good' death

The most important components of a good death, according to health professionals, patients and carers, are:

- good control of pain and symptoms
- clear decision making

- preparation for death
- a sense that things have been completed satisfactorily, such as spiritual or religious tasks, thinking back over life, resolving conflicts, spending time with family and friends, and saying goodbye
- helping others when near death
- being treated as a whole person by empathic health care providers.

Patients and families tend to fear ‘bad’ dying more than death itself. For many people, it is a bad death if they have not had a chance to plan ahead and arrange personal affairs.

Good care of the dying

In recent years, hospices and palliative care facilities and hospitals have designed systems aiming to improve people’s care at the end of life. These include the use of advance care directives, educating health professionals in how to help a person die well, and agreed protocols (known as care pathways) for caring for a dying person.

Care pathways involve care providers from different fields of expertise and are based on the patient’s wishes about important psychological, social, spiritual and practical issues that surround death, as well as physical or medical issues. The emphasis has shifted away from providing life-saving measures at all cost to the best supportive care of a dying patient.

Medically, it is difficult to tell when a person is ‘dying’. Typically, a patient who is entering the terminal phase is unable to get out of bed anymore, is quiet and not communicating, is increasingly drowsy, weak and not moving much. Dying patients are unable to take food or fluids and may become restless, confused or ‘terminally agitated’. However, if a person with a brain tumour becomes like this relatively suddenly after previously having reasonably good quality of life, this may be due to a treatable medical cause (such as an infection), suddenly stopping dexamethasone treatment, or to side effects from medicines.

Sometimes, even after it has become clear to relatives, carers and other health professionals that a patient is dying, the treating team may not accept that standard medical care should stop and the goals of care should change. In this situation, a palliative care team can help everyone involved to understand what is happening and what should be done.

Managing symptoms in dying patients

The aim of palliative care when the person is in the last stage of dying is to provide good symptom control for the patient, support for their carers, and to avoid either deliberately speeding up death or prolonging it artificially.

As death approaches, non-essential medicines should be stopped. All medicines essential for symptom control should be continued and given in a way that the person can manage. Most medicines are given through a small needle inserted under the skin, sometimes via a 24-hour pump (syringe driver). Medicines can also be given through a skin patch or through the rectum.

Pain is the most common and most feared symptom, so painkillers must always be continued. Giving painkillers in doses necessary to provide effective pain relief does not make the person die sooner. Pain is not a common problem for people dying from brain tumours.

Other medicines that may need to be continued until death to control symptoms include medicines to prevent nausea and vomiting, corticosteroids, sedatives and medicines to help confusion.

Soon before death a person may develop noisy breathing ('death rattle') because of fluid in the large airways leading to the lungs. Medicines can control this.

Dying people often become agitated and distressed (terminal restlessness). This can result from something simple like a blocked catheter or uncontrolled pain, but the cause is often not clear. Sedation can be used to control this problem if there is no obvious cause to correct.

Many people dying from brain tumours spend more and more time asleep and eventually go into a coma and die peacefully.

Bereavement and support of families

When the person is close to death, their family and friends may become increasingly distressed as they prepare for the death. Each family will have its own needs for spiritual, religious and psychological support during and after the death of a family member.

After the person has died, most but not all grieving people experience numbness, intense distress, anxiety, yearning and cannot concentrate on anything. They may also experience physical signs of stress such as problems with sleeping and appetite.

Being able to talk about thoughts and feelings, an optimistic personality, social support or a faith help some people to cope with the stress of bereavement. People can be helped to cope with the loss and to adjust to their changed life by encouraging them to share memories, set goals and plan pleasurable activities.

Health professionals should encourage the dead person's family members and carers to have bereavement counselling, particularly if prolonged grief is interfering with activities of daily living and enjoyment of life.

Appendix 1. Working party membership and reviewers

Brain tumour consumer guide working party

We are grateful to members of the working party who generously volunteered their time to develop this Guide:

Emeritus Professor Tom Reeve AC CBE	Senior Medical Advisor, Australian Cancer Network (Convenor until July 2010)
Professor Ian Olver AM	Chief Executive Officer, Cancer Council Australia (Convenor from July 2010)
Professor Michael Barton OAM	Radiation oncologist, NSW (Chair)
Dr Kate Drummond	Neurosurgeon, VIC
Professor Janet Hardy	Palliative care physician, QLD
Dr Elizabeth Hovey	Medical oncologist, NSW
Ms Sally Payne	Consumer representative, International Brain Tumour Alliance, NSW
Mr Denis Strangman	Consumer representative, Chair of International Brain Tumour Alliance, ACT
Associate Professor Jane Turner	Psychiatrist, QLD
Ms Christine Vuletich	Manager, Clinical Guidelines Network, Cancer Council Australia

Reviewers

Dr Michael Bynevelt	Radiologist, WA
Dr Lawrence Cher	Neurologist, VIC
Associate Professor Andrew Cole	Rehabilitation physician, NSW
Dr Ron Freilich	Neurology, VIC
Dr Margot Lehman	Radiation oncology, QLD
Dr Anna Nowak	Medical oncologist, WA
Dr Kevin Patterson	Medical oncologist, SA
Dr Michael Rodriguez	Neuropathologist, NSW
Dr Sally Smith	Epidemiologist, NSW
Dr Charles Teo AM	Neurosurgeon, NSW
Dr Jonathan Wood	Neurologist, NSW

Acknowledgements

This guide has been funded by the Cancer Council Australia to complement the *Clinical Practice Guidelines for the Management of Adult Gliomas: Astrocytomas and Oligodendrogliomas* as a useful information booklet for consumers.

Thank you to:

Dr Elizabeth Hovey, Project Officer, Brain Tumour Guidelines Working Party

Ms Jenni Harman, medical writer, Meducation, NSW for editing the draft document

Ms Mary Russell, Freelance Indexer, Caulfield VIC, for indexing the Guide.

Appendix 2

Glossary

Astrocyte	A type of glial cell
Astrocytoma	A type of tumour that grows from glial cells
Biopsy	The removal of a small sample of tissue from the body, for examination under a microscope, to help diagnose a disease
Benign tumour	A tumour that grows in one place and will not spread to other body parts (not malignant). Benign tumours can be dangerous if they take up too much space inside the skull.
Cancer	A malignant tumour, or the disease caused by a malignant tumour
Central nervous system	The brain and spinal cord
Chemotherapy	The use of drugs that kill cells (cytotoxic drugs) to treat cancer, by killing cancer cells or slowing their growth
CT scan	A computerised tomography scan. This scan uses X-rays to build a picture of the body
Corticosteroids	A type of steroid (hormonal) medicine. Corticosteroids are also made naturally in the body.
Glial cell	A type of cell in the nervous system that surrounds and insulates nerve cells (neurones), holds neurones in place, supplies nutrients and oxygen to neurones, and eliminates dead neurones and germs.
Glioblastoma multiforme (GBM)	A high-grade (more malignant) type of astrocytoma. (The terms “glioblastoma multiforme”, “glioblastoma” and “grade IV astrocytoma” all refer to the same disease.)
Gliomas	The group of brain tumours that includes astrocytomas and oligodendrogliomas
Grade	A measure the degree of abnormality of cancer cells. The grade of a tumour is identified by the pathologist examining the specimen according to an internationally accepted system, and is reported as a number. The grade of the tumour gives an indication of whether it is likely to grow slowly or quickly.
Malignant tumour	A tumour that grows in an uncontrollable way, invading organs and spreading to other body parts through the blood

Metastasis	A cancer that has spread from another part of the body (also known as a secondary cancer)
Mixed glioma	A type of malignant brain tumour
MRI scan	A magnetic resonance imaging scan. This scan uses both magnetism and radio waves to take detailed cross-sectional pictures of the body.
Neurologist	A doctor who specialises in the structure, functioning and diseases of the nervous system (including the brain, spinal cord and peripheral nerves)
Neurone	A cell specialised to transmit electrical nerve impulses, which carry information from one part of the body to the other.
Neurosurgeon	A surgeon who specialises in operations on the nervous system
Primary cancer/tumour	The original cancer. Cells from the primary cancer may break away and be carried to other parts of the body, where secondary cancers may form
Prognosis	The likely outcome of a person's disease
Oligodendrocyte	A type of glial cell
Oligodendroglioma	A type of tumour that is thought to grow from oligodendrocytes, which are cells that normally provide insulation to nerves in the brain
Radiotherapy	The use of radiation, usually X-rays or gamma rays, to kill cancer cells or injure them so they cannot grow and multiply
Rehabilitation	A program that helps a person recover from illness or injury and regain function
Secondary cancer	A cancer that has spread from the original site to another part of the body (also called metastasis)
Seizure	A disruption of the normal electrical impulses of the brain, causing a person to convulse or have other symptoms
Spinal cord	The portion of the central nervous system enclosed in the spinal column, consisting of nerve cells and bundles of nerves connecting all parts of the body with the brain
Steroids	Hormones used in the treatment of disease
Tumour	A growth or 'lump' made of cells that have begun to grow in an unusual way. Tumours may be benign or malignant

Abbreviations

CBT	cognitive–behavioural therapy
CT	computed tomography
DVT	deep vein thrombosis
EEG	electroencephalogram
GBM	glioblastoma multiforme
Gy	Gray (standard unit for measuring radiation)
MRI	magnetic resonance imaging
neuro-PET	positron emission tomography of the brain
neuro-SPECT	single photon emission computed tomography of the brain
PCV	a combination of three chemotherapy drugs: procarbazine, lomustine (also called CCNU) and vincristine
V/Q scan	nuclear ventilation-perfusion scan used for diagnosing a blood clot in the lung (pulmonary embolus)

Index

Index to *Adult gliomas (astrocytomas and oligodendrogliomas): a guide for patients, their families and carers*

- abbreviations 110
- access to services 84
- acknowledgements 107
- acupuncture 69
- Adult gliomas (astrocytomas and oligodendrogliomas): a guide for patients, their families and carers* 7
 - working party membership and reviewers 106
- advance care directives 90
- age and brain tumours 9, 45, 57
- alternative therapies see complementary and alternative therapies
- anaplastic astrocytomas see astrocytomas, anaplastic
- anaplastic oligodendrogliomas see oligodendrogliomas, anaplastic
- anticonvulsant medication 74
 - adjusting doses 95
 - stopping 75
- anxiety 69, 85, 88
- aromatherapy 69
- astrocyte 108
- astrocytomas 10
 - defined 8, 108
 - grade I 10
 - grade II see astrocytomas, low-grade
 - grade III see astrocytomas, anaplastic
 - grade IV see glioblastoma multiformes (GBM)
 - high-grade see astrocytomas, high-grade
 - incidence of 10
 - low-grade see astrocytomas, low-grade
 - pilocytic 10
 - risk factors 11
 - in spinal cord 10
- astrocytomas, anaplastic 47
 - chemotherapy 52
 - radiotherapy 50
 - survival 12, 47
 - see also astrocytomas, high-grade
- astrocytomas, high-grade 10
 - brain scans 46
 - chemotherapy 49–50, 52
 - chemotherapy for recurring tumours 54
 - diagnosis 45–7
 - grading 46–7
 - healthcare professionals 48
 - key points 44–5
 - prognosis 47–8
 - radiotherapy 50–2
 - recurrence 53–5
 - specimens 46–7
 - surgery 48–50
 - surgery for recurring tumours 53–4
 - survival 12, 47–8
 - symptoms 45–6
 - before treatment 48
 - treatment 48–52
- astrocytomas, low-grade 10
 - brain scans 38
 - chemotherapy 43
 - diagnosis 38–9

- key points 37
- radiotherapy 40–2
- specimens 38–9
- surgery 39–40
- surgery not the best option 40
- survival 12
- symptoms 38
 - before treatment 39
 - treatment 39–43
 - waiting (conservative approach) 42–3
- benefits see evidence of benefits
- benign tumours 8, 108
- bereavement 105
- bevacizumab 55
- beyondblue 91
- biopsy
 - astrocytomas, high-grade 46–7
 - astrocytomas, low-grade 38–9
 - defined 108
 - needle 33, 38, 58
 - oligodendrogliomas 58–9
 - safety issues 39, 46
 - surgical 33
- bladder problems 102
- blood clots 79
 - key points 72
 - prevention 79–80
 - treatment 80
- body appearance 86
- Boswellia serrata* 70
- bowel problems 102
- brachytherapy 51
- brain function 27–8, 81
- brain scans
 - astrocytomas, high-grade 46
 - astrocytomas, low-grade 38
 - follow-up 32, 62, 64
 - key points 29
 - limitations of 32
 - oligodendrogliomas 58
 - reasons for 29–30
 - after surgery 32
 - types of 30–1
- Brain Tumour Alliance Australia 91
- brain tumours
 - and age 9, 57
 - benign 8
 - causes 11–12
 - incidence of 9
 - key points 8
 - malignant 8
 - and men 9, 45
 - participating in research 20–4
 - screening programs 12
 - symptoms of 25–32
 - types of 10–11
 - and women 9, 45
 - see also astrocytomas; oligodendrogliomas

- cancer 8, 108
 - secondary (metastatic) 9
- Cancer Council Australia 91
- cancer genetics services 11
- Cancer Institute NSW 91
- cannabis 69
- care teams *see* healthcare professionals
- carers
 - and bereavement 105
 - information for 15–16
 - and palliative care 98, 100
 - support for 14
 - surrogate decision makers 17–18, 89
- carmustine wafers 49–50
- central nervous system (CNS) 8, 108
- checklist for information on tests and procedures 19
- chemotherapy
 - astrocytomas, high-grade 49–50, 52
 - astrocytomas, low-grade 43
 - and complementary and alternative therapies 69
 - defined 108
 - evidence of benefits 52, 63
 - glioblastoma multiformes (GBM) 50
 - information booklets available 43, 83
 - inplants 49–50
 - oligoastrocytomas 63–4
 - oligodendrogliomas 63
 - for recurring tumours 54, 65–6
 - side effects 43, 83
 - wafers 49–50
- children
 - information booklets available 16
 - and pilocytic astrocytomas 10
 - telling about diagnosis 16
- clinical psychologists 93
- clinical recurrence 53, 65
- clinical trials
 - and chemotherapy 52, 63
 - and complementary and alternative therapies 69
 - and consent 23
 - key points 20
 - participating in 23–4
 - phases of 21
 - purpose of 20–1
 - and radiotherapy 41, 50–1
 - who approves? 22
 - who conducts? 22
 - who participates in? 22–3
 - why important 20
- cognitive-behavioural therapy (CBT) 90
- cognitive impairment 27–8, 81, 87–8, 101
 - key points 84
- complementary and alternative therapies
 - defined 68
 - further information 70
 - information booklets available 71
 - key points 67
 - possible benefits 68–70
 - types of 67–8
 - unwanted effects 70

- computed tomography scans *see* CT scans
- consent and clinical trials 23
- conservative approach to treatment
 - astrocytomas, low-grade 42–3
 - oligodendrogliomas 61
- consultations and information provision 15–16
- Cooperative Trials Group for Neuro-Oncology (COGNO) 22, 23
- cooperative oncology (cancer) groups 22
- coping strategies 90–1
 - key points 85
 - and treatment 18–19
- corticosteroids 108
 - at end of life 103
 - side effects 81–2, 103
 - see also* dexamethasone
- counselling 16, 69, 75
- CT scans 30
 - astrocytomas, high-grade 46
 - astrocytomas, low-grade 38
 - defined 108
 - oligodendrogliomas 58
- cultural issues 15

- death
 - care of dying 103–5
 - 'good' 103–4
- decision making
 - participating in clinical trials 23–4
 - planning ahead 85, 89–90, 99–100
 - on treatment 17–18, 39, 48, 60, 89–90
- deep vein thrombosis (DVT) 72, 79–80
- delirium 89
- dementia 28
- depression 69, 88
 - and euthanasia 100
 - information booklets available 88
 - key points 85
- dermatitis *see* skin reactions
- dexamethasone 52, 80
 - adjusting doses 95
 - and headaches 27
 - and ibuprofen 27
 - key points 72
 - side effects 81–2
- diagnosis
 - accuracy 35
 - astrocytomas, high-grade 45–7
 - astrocytomas, low-grade 38–9
 - information about 15–16
 - making 34–5
 - oligodendrogliomas 57–9
 - seizures 74
 - symptoms at time of 25–6
 - telling others 16
- doctors *see* healthcare professionals
- driving 95
 - information booklets available 77
 - licensing authorities 77
 - and rehabilitation 93
 - and seizures 76–7, 86

- electroencephalogram (EEG) 74
- end of life
 - care of dying 103–5
 - symptom management 101–3
- euthanasia 100
- evidence of benefits
 - chemotherapy 52, 63
 - chemotherapy for recurring tumours 54
 - complementary and alternative therapies 68–9
 - radiotherapy 41, 50–1, 62
- familial cancer clinics 11
- families
 - and bereavement 105
 - information for 15–16
 - and palliative care 98, 100
 - planning ahead 89–90
 - support for 14
 - surrogate decision makers 17–18, 89
- fatigue 100
- feeding issues 101–2
- first aid for seizures 75–6
- fluids at end of life 101–2
- follow-up 94–5
 - brain scans 32, 62, 64
 - key points 94–5
 - oligodendrogliomas 64
- frankincense 70
- frozen sections 34
- gamma-knife surgery 51
- genetics
 - inherited tendency 11
 - 1p/19q co-deletion 59–60, 63
 - testing 59
- glial cells 10, 108
- glioblastoma multiformes (GBM) 10, 47
 - chemotherapy 50, 52
 - defined 8, 108
 - radiotherapy 50
 - survival 12, 47
 - see also astrocytomas, high-grade
- gliomas
 - defined 8, 108
 - see also brain tumours
- glossary 108–9
- grading 34–5
 - astrocytomas, high-grade 46–7
 - defined 8–9, 108
 - oligodendrogliomas 59
- group support 91
- headaches 26–7, 100
 - treatment of 27
- health system
 - access to services 84
 - counselling 16
 - dealing with medical staff 14–15
 - getting help 13–14

- key points 13
- palliative care 97–100
- see also decision making
- healthcare professionals
 - astrocytomas, high-grade 48
 - and bereavement 105
 - communication with 13–14
 - decisions about treatment 17–18
 - discussing prognosis 16
 - and follow-up 94
 - information provision 15, 89–90
 - palliative care 97
 - and rehabilitation 92–3
 - second opinions 14–15
 - working with 14
- heparin 79–80
- herbal remedies 69–70
- homeopathy 70
- hospices 98, 104
- hospitals and palliative care 98, 104
- ibuprofen 27
- imaging
 - astrocytomas, high-grade 46
 - astrocytomas, low-grade 38
 - follow-up 32, 62, 64
 - key points 29
 - nuclear medicine 31
 - oligodendrogliomas 58
 - reasons for 20–30
 - after surgery 32
 - types of 30–1
- infections and corticosteroids 82
- information
 - about diagnosis 15
 - booklets available 16, 43, 71, 77, 83, 88, 99
 - checklist for tests and procedures 19
 - and clinical trials 23, 36
 - and coping with medical procedures and treatment 18–19
 - and cultural issues 15
 - and decision making 89–90
 - discussing prognosis 16
 - telling others 16
 - and tissue banking 36
- insomnia 70
- institutions and clinical trials 22
- interpreter services 15
- ionising radiation exposure as risk factor 11
- key points
 - access to services 84
 - astrocytomas, high-grade 44–5
 - astrocytomas, low-grade 37
 - blood clots 72
 - brain scans 29
 - brain tumours 8
 - clinical trials 20
 - cognitive impairment 84
 - complementary and alternative therapies 67
 - copng strategies 85

- follow-up 94–5
- health system 13
- mental health 85
- oedema management 73
- oligodendrogliomas 56–7
- palliative care 96
- pathology 33
- personality changes 84
- physical problems 84
- psychosocial issues 84–5
- quality of life 85
- rehabilitation 92
- seizures 72
- skin reactions 72
- symptoms 25

- magnetic resonance imaging scan see MRI scans
- malignant tumours 9, 108
- massage 69
- medical problems 13–14
- medical procedures
 - coping with 18
 - information checklist 18
- medical staff see healthcare professionals
- medicines
 - adjusting doses 95
 - and anticonvulsant medication 74
 - and complementary and alternative therapies 70
 - in dying patients 104–5
 - interactions between 83
 - side effects 83
 - and skin reactions 77–8
- meditation 69
- men and brain tumours 9, 45
- mental health 85, 88–9
- metastasis 9, 109
- migraines see headaches
- mixed glioma 109
- mixed oligoastrocytoma 10
- MRI scans
 - astrocytomas, high-grade 46
 - astrocytomas, low-grade 38
 - defined 109
 - follow-up 32, 62, 64
 - oligodendrogliomas 58
 - reasons for 26
 - for recurring tumours 53
 - safety issues 31
 - during surgery 30–1
 - after surgery 32
- multidisciplinary teams see healthcare professionals

- National Health and Medical Research Council 22
- nausea and vomiting 69, 101
- needle biopsy 33, 38, 58
- nerve damage, symptoms caused by 28
- neuro-PET 31
- neuro-SPECT 31
- neurologists 109
- neurones 109

- neuropsychologists 93
- neurosurgeons 109
- non-ionising radiation exposure as risk factor 11
- nuclear medicine 31

- occupational therapists 92–3
- oedema management 27, 52, 80

- key points 73
 - side effects 81–2

- oligoastrocytomas 59
 - chemotherapy 63–4, 65–6
 - follow-up 64
 - mixed 10
 - radiotherapy 62, 63
 - recurrence 64–6
 - surgery 60–1, 63
 - treatment 63–4

- oligodendrocytes 109

- oligodendrogliomas 10–11

- anaplastic 10, 12
 - brain scans 58
 - chemotherapy 63, 65–6
 - defined 9, 109
 - diagnosis 57–9
 - follow-up 64
 - grading 57, 59
 - high-grade 10, 57, 59, 63–6
 - incidence of 11
 - key points 56–7
 - low-grade 10, 12, 57, 59, 66
 - prognosis 59–60
 - radiotherapy 61–2
 - recurrence 64–6
 - risk factors 11
 - seizures 10
 - specimens 58
 - in spinal cord 10
 - surgery 60–1
 - surgery for recurring tumours 65
 - surgery not the best option 61
 - survival 10, 12, 59–60
 - symptoms 57–8
 - before treatment 60
 - treatment 60–3
 - waiting (conservative approach) 61

- 1p/19q co-deletion (genetic feature) 59–60, 63

- osteoporosis 82

- outlook see prognosis

- pain-killers

- and dying patients 104–5
 - and headaches 27

- palliative care

- care of dying 103–5
 - defined 97
 - at home 98
 - information booklets available 99
 - key points 96
 - organising 97
 - planning ahead 99–100

- when to start? 98–9
- palliative care units 98, 104
- pathology
 - astrocytomas, high-grade 46–7
 - astrocytomas, low-grade 38–9
 - and diagnosis 33–6
 - key points 33
 - oligodendrogliomas 58–9
 - safety issues 39
 - during surgery 34, 38–9
- pathology laboratories 33–6
- pathology reports 35
- PCV (procarbazine plus lomustine (CCNU) plus vincristine) 63, 64
- personality changes 84, 86–7
- pharmaceutical companies and clinical trials 22
- phase I clinical trials 21
- phase II clinical trials 21
- phase III clinical trials 21
- phase IV clinical trials 21
- physical problems 84, 86
- physiotherapists 92
- pilocytic astrocytomas 10
- planning ahead 89–90, 99–100
 - key points 85
- pressure sores 102–3
- primary tumours 9, 109
- procedures see medical procedures
- prognosis 109
 - astrocytomas, high-grade 47–8
 - discussing 16
 - oligodendrogliomas 59–60
- progression 53, 65
- pseudo-progression 53
- psychological therapies 69
- psychologists 93
- psychosocial issues 84–5
- psychotherapy, supportive 90–1
- quality of life
 - and complementary and alternative therapies 69–70
 - concerns 85, 90
 - key points 85
- questions to ask about tests and procedures 19
- radiation exposure as risk factor 11
- radiological recurrence 53, 65
- radiotherapy
 - astrocytomas, high-grade 50–2
 - astrocytomas, low-grade 40–2
 - best time for 41, 61–2
 - and brain damage 42
 - and complementary and alternative therapies 69
 - defined 109
 - evidence of benefits 41, 50–1, 62
 - oligoastrocytomas 62, 63
 - oligodendrogliomas 61–2
 - for recurring tumours 65
 - schedule for 51
 - for seizures 75
 - side effects 42, 81

- and skin reactions 78–9
- rashes see skin reactions
- recurrence 53, 65
 - astrocytomas, high-grade 53–5
 - oligoastrocytomas 64–6
 - oligodendrogliomas 64–6
- recurring tumours 53, 65
 - chemotherapy 54, 65–6
 - MRI scans 53
 - radiotherapy 65
 - surgery 53–4, 65
- rehabilitation 92, 109
 - aims of 92–3
 - and driving 93
 - key points 92
- relaxation 69, 90
- research see clinical trials
- respite care 98
- safety issues
 - biopsy 39, 46
 - MRI scans 31
 - seizures 75–6
- salai (herb) 70
- screening programs 12
- second opinions 14–15
- secondary (metastatic) cancer 9, 109
- seizures 28, 73, 86
 - anticonvulsant medication 74–5
 - controlling 74
 - counselling 75
 - defined 109
 - diagnosis 74
 - and driving 76–7, 86
 - at end of life 102
 - first aid for 75–6
 - key points 72
 - radiotherapy 75
 - safety issues 75–6
 - surgery for 75
 - types of 73
- side effects 13–14
 - chemotherapy 43, 83
 - complementary and alternative therapies 70
 - corticosteroids 103
 - dexamethasone 81–2
 - medicines 83
 - radiotherapy 42, 81
 - skin reactions 77–9
- skin reactions
 - caused by radiotherapy 78–9
 - key points 72
 - side effects of medicines 77–8
- social issues 84–5
- social workers 93
- specimens 33
 - astrocytomas, high-grade 46–7
 - astrocytomas, low-grade 38–9
 - oligodendrogliomas 58
 - processing 34

- special tests 36
- speech pathologists 93
- spinal cord 109
 - astrocytomas in 10
- steroids 109
 - see also corticosteroids
- stereotactic radiosurgery 51
- support groups 91
- support services 14
- surgery
 - aims of 40, 49, 61
 - astrocytomas, high-grade 48–50
 - astrocytomas, low-grade 39–40
 - best time for 40
 - brain scans after 32
 - inserting chemotherapy wafers 49–50
 - MRI scans during 30
 - not the best option 40, 61
 - oligoastrocytomas 63
 - oligodendrogliomas 60–1, 63
 - pathology during 34
 - for recurring tumours 53–4, 65
 - for seizures 75
- surgical biopsy 33, 38–9, 58
- surrogate decision makers 17–18, 89
- survival 12
 - astrocytomas, high-grade 47–8
 - oligodendrogliomas 10, 59–60
- swallowing 101
- swelling in the brain 27, 52, 70, 80, 81–2
 - key points 73
- symptoms
 - astrocytomas, high-grade 45–6
 - astrocytomas, low-grade 38
 - caused by nerve damage 28
 - cognitive impairment 27–8
 - at diagnosis 25–6
 - in dying patients 104–5
 - end of life 101–3
 - key points 25
 - nausea and vomiting 69
 - oligodendrogliomas 57–8
 - and palliative care 100–1
- temozolomide 43, 54, 63, 64
- tests
 - copied with 18
 - information checklist 19
 - see also pathology
- thalidomide 55
- thinking, problems with 27–8, 81, 87–8, 101
 - key points 84
- tissue banks 36
- Trans Tasman Radiation Oncology Group (TROG) 22
- treatment
 - astrocytomas, high-grade 48–52
 - astrocytomas, low-grade 39–43
 - blood clots 80
 - conservative approach 42–3, 61
 - copied with 18–19

- of headaches 27
- make decisions on 17–18, 39, 48, 60, 89–90
- oligoastrocytomas 63–4
- oligodendrogliomas 60–3
- surrogate decision makers 17–18
- see also palliative care
- tumours
 - benign 8, 108
 - defined 9, 109
 - grading 8–9, 34–5
 - malignant 9
 - primary 9, 109
 - recurrence 53, 65
 - see also brain tumours
- valerian 70
- venous thromboembolism 72, 79–80
- vomiting 69, 101
- waiting (conservative approach)
 - astrocytomas, low-grade 42–3
 - oligodendrogliomas 61
- wills 90
- women and brain tumours 9, 45
- X-rays see radiotherapy

