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# Palliative Care

PATIENT GUIDE

# What is palliative care?



- Palliative care involves co-ordinated care from doctors, nurses and allied health professionals that aims to maximise the quality of life for people and their families who face problems associated with a life-limiting condition.
- Palliative care provides physical, psychological, emotional, spiritual and cultural support for the patient, their family, whānau and friends. It involves planning ahead to minimise distress, rather than just intervening when there is a crisis.
- Palliative care improves patients' symptom control and general wellbeing. It may be helpful if you suffer from pain, stress or other symptoms that affect your quality of life.
- Palliative care can be given at home, or in a hospital, community clinic, rest home, or hospice. Depending on your situation and extent of symptoms, palliative care may be appropriate as soon as the diagnosis of your brain tumour is made. It may be provided in conjunction with active treatment or when active treatment is no longer appropriate.
- You may be living with your brain tumour for a long time. The focus is on managing symptoms so that you can lead as good a quality of life as is possible, for as long as possible.
- Prevention and relief of suffering is done through early identification, assessment and treatment of pain and other problems. The aim is to help you and your family with your needs, expectations, hopes and fears.
- Palliative care is not limited to end of life care. Many people think that palliative care is end of life care, but it is more than that. Palliative care may be offered at any stage of your illness, depending on your symptom burden, and is complementary to treatment.



## Who delivers palliative care?

Most large city hospitals have a palliative care team consisting of doctors, specialist nurses and allied health workers who can review patients in hospital. Community palliative care is commonly delivered by general practitioners (GPs) with support from local palliative care teams.

Examples of how palliative care team members may provide care include:

- Palliative care nurses – provide general care and help you manage pain and other symptoms. They often act as the main point of contact between you and the rest of your care team.
- Social workers – provide support to you and your family and help connect you with the services and resources you require.
- Palliative medicine specialists – doctors who have undergone specialist training to care for patients with life-limiting conditions provide symptom assessment and management such as pain.
- Physiotherapists – help improve strength and movement.
- Occupational therapists – focus on helping you with daily tasks and activities.
- Grief and bereavement counsellor – help guide and support families experiencing grief and loss.

## What does palliative care involve?

The palliative care approach focuses on meeting the needs of the whole person not just treating their condition.

Palliative care should involve:

- An explanation of your illness, treatments, and medications to you and your caregiver.
- Symptom management e.g. pain, to help improve your quality of life and relieve any suffering.
- Support with managing personal care (showering, eating, etc).
- Advice on self-care, such as healthy eating, exercise, and relaxation.
- Guidance on ways in which you can receive support and ways you can network with others.
- Help with decision-making.
- Assistance with advanced care planning (ACP), so you can make informed and active decisions about how you want to live and die.



## 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 rest home.

When palliative care is given in the person's home, it is given mainly by their GP, with help from community palliative care teams. These teams are often part of local hospices and will usually have specialist care nurses and a specialist palliative care physician as well as counselors, pastoral care workers and volunteers. Physiotherapy, nutritional support, occupational therapy and home help may also be available.

## Hospitals

Patients being cared for at home or somewhere else may need to be admitted to hospital, even if they are no longer receiving treatment for their brain tumour. 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 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.

## Respite care

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 some 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 earlier in their illness and even at the time of diagnosis.

Because palliative care 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 brain tumour journey, particularly but not limited to 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 multidisciplinary team (MDT) which is providing the treatment. Doctors should offer people 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.

## 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 brain tumour patients prefer to be given some information about prognosis when they are first diagnosed. The amount of information given and the distress 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 give specific dates.

Palliative care experts could help patients with high grade brain tumours and their families and carers, to ask appropriate questions about what is

likely to happen to the person in future and what to expect from treatment.

Individuals prepare for death by completing any 'unfinished business', for example, signing a legal will, contacting loved ones, or legally delegating the management of personal affairs to someone else.

## Advanced care planning

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. Formerly recording the person's wishes in writing is called advanced care planning (ACP).

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. Such specific treatment decisions can be formally documented as Advance Directives as part of the ACP. 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.

## 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 treatment 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 treatment of pain.

General management for fatigue can involve teaching the person ways to conserve their energy, tailored exercise programmes, 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. Headaches caused by brain tumours are also treated with simple pain killers, such as paracetamol or nonsteroidal anti-inflammatory drugs such as ibuprofen. Sometimes opioid (morphine and morphine like drugs) is required.

### 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 or prochlorperazine may be used.

### Cognitive impairment (problems with thinking)

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, radiotherapy, 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.

## What is the optimum standard of care according to international guidelines?

The optimum standard of care states the minimum level of care we should expect. Sometimes, for a variety of reasons, our health service may not be able to meet the standards.

- A holistic needs assessment.
- Support from specialist palliative care services should be available if required.
- You can expect to be given information on local specialist palliative care services.
- You should have the opportunity for regular systematic needs, assessments and discussions with local specialist palliative care services about further involvement as needed.
- You and your family can expect to have the chance to discuss your wishes for the future, which may include discussing where you wish to be cared for as your disease progresses (advance care planning). It may also include the right to refuse or consent to a particular treatment or procedure at a future time when they have become incompetent (advance directive).
- Your wishes should be observed, where possible. Sometimes this is not possible, but clinicians will always endeavour to observe your wishes. Things to consider are resuscitation and use of antibiotics.
- Talking about these early will help everyone.

## What does Brain Tumour Support NZ think I should expect?

- A timely Advance Care Plan (ACP) for everyone who wishes to have a say in his or her management towards the end of life.
- All staff involved in your care to be aware of your wishes through the ACP and advance directive.
- Regular opportunities to discuss ongoing palliative care needs, which include a management plan. This can avoid unnecessary hospital admissions.
- Your hospital to communicate with your GP and community palliative care team.

## What questions could I ask?

- What support is available to my family and me?
- How do I begin to have those difficult conversations?
- When the time arrives, where can I be looked after?
- What financial and physical support is available for me so that I can be cared for in my preferred place of care?
- How often will my needs be assessed?
- How can I ensure that my wishes will be met?
- How can I access palliative care services?
- Are there any clinical trials available?

## Sources



### **brainstrust**

#### **Patient Guide (accessed August 2019)**

[brainstrust.org.uk/brain-tumour-support/navigating-your-pathway/patient-guides](https://brainstrust.org.uk/brain-tumour-support/navigating-your-pathway/patient-guides)

### **Cancer Council Australia/Clinical Oncological Society of Australia**

#### **Adult gliomas (astrocytomas and oligodendrogliomas): a guide for patients, their families and carers (April 2011)**

[cancer.org.au/content/pdf/HealthProfessionals/ClinicalGuidelines/Adult\\_Glioma\\_Consumer\\_Guide\\_FINAL\\_bookmarked.pdf](https://cancer.org.au/content/pdf/HealthProfessionals/ClinicalGuidelines/Adult_Glioma_Consumer_Guide_FINAL_bookmarked.pdf)

### **Hospice New Zealand**

[hospice.org.nz](https://hospice.org.nz)

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### **Disclaimer**

This patient guide reflects current recommendations from international clinical guidelines for the management of primary adult brain tumours. It is not intended to take the place of medical advice. A patient's GP or specialist may provide them with new or different information which is more appropriate to their needs.

New Zealand does not have its own set of clinical practice guidelines for the management of brain tumours. New Zealand doctors will typically refer to international guidelines, from organisations such as: the UK's National Institute for Health and Care Excellence (NICE); the European Society of Medical Oncology (ESMO); the European Association of Neuro-Oncology (EANO); Cancer Council Australia; and the USA's National Comprehensive Care Network (NCCN). Links to these international guidelines can be found in our Online Resources directory.

**June 2022**

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