

Information for patients with a brain tumor, their family and friends: when treating the disease is no longer possible.

Online: <https://hersentumorcentrum.nl/eol-patienten/>

Please note!

A doctor can never know how long someone will survive. Sometimes, a patient's condition recovers and the initial indication of time may not be correct.

It is possible that you do not feel ready for certain information. If so, save this information for later. You can also choose to let someone else read it first.

Introduction

This information is intended for patients with a brain tumor, their family and friends. It is about the phase where the brain tumor grows and treatment of the tumor has become impossible – which is known as palliative care. As soon as anti-tumor treatment is no longer possible, the symptomatic or palliative phase commences. Generally, care will be transferred to the general practitioner, the hospice doctor or the nursing home doctor.

This document explains the care that can be offered and how the course of this next phase will be decided and will contain tips and references to support family, friends and caregivers. Euthanasia and palliative sedation will be discussed and also the use of dexamethasone and possible side effects of dexamethasone. The appendix will explain possible symptoms of a brain tumor and the possibilities of treating this.

Palliative care

This is a difficult time as you come to terms with and start processing the news, for both you and your loved ones. Palliative care can provide different treatment options to reduce symptoms in this phase and prevent suffering. Consideration is given to physical, psychological, social and fulfillment needs and those of loved ones are also taken into account. Caregivers can help with important decisions about the type of care and the manner in which this is will be organized for you.

Together, you will have lots of difficult questions, such as:

- 'What symptoms will I get?'
- 'Will I experience a lot of pain?'
- 'Are there treatments that I still want or don't want?'
- 'What will be my cause of death?'
- 'Where will I die?'
- 'What will happen to my children and partner when I'm not around anymore?'
- 'How do I organize the finances?'

For example, it is especially important to think about and discuss well in advance where you may wish to die: at home or in a hospice? Another consideration is when do you want to stop going for treatment in hospital? You may wish to avoid unnecessary travel in the last phase, when your condition does not allow it and time is valuable to be with your loved ones.

Discuss these questions with your family, friends and loved ones as well as your physician. Your doctor can refer you if needed for example, to a specialized (district) nurse, social worker, psychologist, spiritual counsellor, physiotherapist or dietitian. This is not easy so discuss it when you are ready, but consider your time span. Discussing these subjects in time can bring some relief. There are not always answers to your questions, but we aim to provide some clarity which will have a positive effect on the quality of your life over the next period of time.

The expected course

Please note!

The expected course of disease for patients with a brain tumor is never exactly predictable. Therefore, it is impossible to give an estimation of the life expectancy for an individual.

The symptoms discussed below have a link to the [appendix 'dexamethasone, symptoms and treatment'](#). The appendix will go into detail per symptom and how this symptom can be treated.

Neurological symptoms

As a result of tumor growth, it is likely that [neurological deficits](#) will occur or existing neurological deficits will increase. What kind of deficits will occur depends on the location of the brain tumor. Possible symptoms are paralysis, difficulties with walking, linguistic difficulties, a restricted field of vision (hemianopsia) and problems with attention, memory or concentration. [Behavior change](#) can also occur. You may become more passive over time. Unfortunately, it is also possible that you get irritated or aggressive more quickly, your care givers may notice this as you will not be aware of these changes in yourself. Sometimes, [epileptic seizures](#) can occur or occur more often but medication is usually effective in treating seizures.

Because of the neurological deficits (and epilepsy), you will become less independent and will need more and more care from others. You may become bedridden.

This is difficult to read and absorb, take your time to reflect and consider your possible needs.

Complications

Because of the deteriorating physical condition of patients with a brain tumor, complications can occur. Examples are infections (for instance in the lungs, pneumonia) or pulmonary embolisms (a blood clot in the arteries in the lungs). These complications can be life-threatening so it is important to have clear agreements with your health care providers about what complications should or should no longer be treated. Also, you may need to consider whether you still go to the hospital or not.

Talk to your doctor about your preferences concerning resuscitation because the enlarged brain tumor is often the cause of the respiratory or cardiac arrest. Unfortunately, the chance of a successful resuscitation (without increased brain damage) is very small.

The end of life

In most cases, patients with a brain tumor de cease as a direct result of the brain tumor.

In the early phase, as a result of the growing tumor, the intracranial pressure rises. This can cause symptoms like [headache](#), [nausea or vomiting](#) which are treatable with medication (nausea and vomiting are uncommon).

In the later phase, the rising pressure in the head causes [decreased consciousness](#) producing an increased need for sleep, eventually you will slip into a coma and become unable to make contact your surroundings. Sometimes, your consciousness can vary. Ultimately, the intracranial pressure increases further, and causes the heart and breathing to stop. At this time, you are already in a deep coma, and so you will be unaware. This process of passing runs peacefully, within a period of hours to days.

Palliative sedation

In most cases symptoms of the tumor can be treated effectively with medication in the last phase of life. However, Palliative sedation is given to patients who are dying and are suffering unbearably. This deliberately reduces consciousness with the use of medication given intravenously (through an IV). Palliative sedation is only used when suffering cannot be treated effectively in other ways (for example with different medication).

Support for family, friends and other caregivers

An important part of the care in the last phase of life falls in the hands of the loved ones. In most cases, that is primarily the partner. Taking care of a loved one with a brain tumor in this phase is very hard and emotionally and physically tiring. Having someone at home in this phase often means having to be available 24 hours per day. In the Netherlands informal care is supported by:

- The organization for volunteers for palliative and terminal care (VPTZ)
 - Phone: +31-(0)30-6596266
 - Website: www.vptz.nl
- Mezzo (national association for everyone who takes care of someone else):
Phone: +31-(0)900-2020496
Email: mantelzorglijn@mezzo.nl
website: www.demantelzorger.nl
- Professional organization for all caregivers: <https://paletwelzijn.nl/mantelzorg/>
- Info for employers of caregivers: <https://www.mantelzorginfopunt.nl/>
- Some support to engage in activities for yourself: www.handjehelpen.nl

Further information

In case you have any questions, please contact your treating physician. Reliable information can be found on these Dutch websites about brain tumors (most are only in Dutch):

www.hersentumor.nl

www.hersentumorcentrum.nl

The following websites contain lots of information about the end-of-life phase and palliative care:

<http://www.alsjernetmeerbeterwordt.nl/>

<https://getpalliativecare.org/handouts-for-patients-and-families/>

<http://thuisarts.nl/levenseinde/>

<http://www.gewoondood.nl/>

Colophon

This informative letters for doctors, patients, family and friends** about the end of life for brain tumor patients is written by dr. Walter Taal¹ under the aegis of the LWNO. Translated by Eva van Diest.¹

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**In addition to this informative document for patients, family and friends, there is a document specifically for doctors. See <https://hersentumorcentrum.nl/eol-artsen/>

Appendix: dexamethasone, symptoms and treatment

Below the use of dexamethasone and symptoms that can be caused by a brain tumor will be discussed. Also, we will go into how these symptoms can be treated.

Dexamethasone

Dexamethasone will be prescribed for almost all brain tumor patients.

The effect of dexamethasone

Dexamethasone is a type of corticosteroid. Another corticosteroid is prednisone. The brain tumor causes an inflammatory reaction. This causes swelling of the brain tissue, also called edema. Corticosteroids have an anti-inflammatory effect, and therefore reduce the swelling. This decreases the pressure inside the head. This can relieve symptoms such as [neurological deficits](#) and [headaches](#).

Side effects of dexamethasone

Dexamethasone is known to have lots of side effects, especially when patients use this for a longer period. All adverse effects are discussed in the package insert of dexamethasone. The most common side effects will be discussed below.

Stomach issues

In case of any stomach issues (such as heartburn or reflux) after starting dexamethasone, starting a stomach protector is advised. Examples of acid inhibitors are pantoprazole or esomeprazole.

High blood sugars

Dexamethasone can cause high blood sugars. This can cause you to feel thirstier, drink more than usual and urinate more often. However, blood sugars can rise to life-threatening levels without the patient experiencing any symptoms. For this reason, it is important to check your blood sugar once or twice per week. This is possible with a finger stick test.

Insomnia

Dexamethasone can cause [insomnia](#). In that case, it can be helpful to take the entire dose of the day in the morning. Discuss this with your treating physician. Prescribing a sleeping draft is also an option.

Prevention of osteoporosis

Using a higher dose of dexamethasone (>2,25mg/day) for a longer period of time can cause osteoporosis. Try to keep moving to prevent this as much as possible.

Inflammation/infection

Dexamethasone inhibits the immune system. This can cause inflammation and/or infection. A yeast infection (candida) in the mouth is a frequent problem. This causes a white coating on the tongue or mucous membranes in the mouth. If the esophagus is also infected, this can result in intense pain when swallowing. Usually, this yeast infection is easily treatable with an oral gel (miconazole or nystatin). Discuss this with your treating physician.

Confusion

Dexamethasone can cause psychiatric symptoms. Usually these occur within weeks after starting dexamethasone. The brain tumor can also be a cause of psychiatric symptoms. Therefore, the exact cause is not always easily identifiable. Dexamethasone often causes patients to be energetic, hyperactive and disinhibited. People can also become irritated more quickly, chaotic and/or restless. Additionally, aggressive behavior can occur. In these cases, the preference is to lower the dose of dexamethasone. Always discuss these symptoms with your doctor.

The dose of dexamethasone

The dose is highly dependent on personal circumstances. It is known that in most cases, a dose higher than 16mg is not useful. In case of an increase in neurologic deficits and/or headaches, sometimes the dosage of dexamethasone is increased extremely to ensure a fast effect. Afterwards, the dose can be lowered gradually until the correct dose. When the intended effect is not achieved, it is better to return to the usual dose. Sometimes, doctors choose to prescribe a higher dose of dexamethasone once for a fast effect (or example a one-off dose of 8 or 10mg). Always discuss the dexamethasone dosage with your doctor, and never deviate from your prescription without talking to a health care professional.

Please note!

Not all symptoms mentioned below will always arise. This depends on different factors, such as the location of the brain tumor. Your doctor can often give an indication of which symptoms you can expect. Even so, it is not always possible to predict exactly what symptoms patients will get. You can also only read the texts about the symptoms that you have.

The mentioned symptoms are not always the direct result of the brain tumor. Sometimes there can be another cause. This is possibly a cause that can be treated, for example an adverse effect of prescribed medication. Therefore, it is important to always discuss new or increased symptoms with your health care professional(s).

Increased neurological deficits

In most cases, the brain tumor causes physical disabilities (neurological deficits). For example, some patients have difficulties walking or cannot move their arm properly. This is not treatable, except for (increasing the dose of) dexamethasone. Sometimes assistive devices can be of added value. Examples are canes, wheelchairs, walkers and a medical bed. Your general practitioner knows your individual situation, and thus your needs, best and can often be of assistance in arranging assistive devices. Sometimes the increase in (neurological) symptoms is caused by your medication. Therefore, always consult your treating physician.

Behavior change

Behavior change is quite frequent in the case of a brain tumor. Mostly, patients who experience these symptoms are not aware of them. In most cases, patients react slower and less spontaneous. They show less emotions and become more and more passive. This results in patients needing others to tell them what to do and when to do it. This is untreatable.

In some cases, the opposite occurs, and patients become disinhibited and hyperactive. They get irritated easily, become chaotic and restless. On rare occasions patients can become confused and aggressive. It is important to discuss this with your doctor, because there can be several factors contributing to this behavior. Sometimes these factors can be treated, for example with medication.

Epilepsy

Not everyone with a brain tumor will get epileptic seizures. These seizures result from a sudden, temporary 'short circuit' of the electric nerve messages in the brain. Seizures occur in different ways. The symptoms depend on the location in the brain where this 'short circuit' happens. Someone can

show tonic muscular contractions, make strange movements, smell a specific scent, be absent and/or lose consciousness.

In general, epileptic seizures are treatable with medication. There are two types of medication to treat epilepsy: medication to prevent seizures and medication to suppress seizures.

Medication to prevent seizures

The most commonly used medication to prevent epileptic seizure are: levetiracetam, sodium valproate, lacosamide, clobazam, carbamazepine, phenytoine, oxcarbazepine, topiramate, gabapentine and lamotrigine. Generally, you start on a low dose and the dose is increased if the effect is insufficient. In most cases it is necessary to increase the dose slowly.

Medication to suppress seizures

If a seizure with tonic muscular contractions continues for too long, it can be necessary to administer medication to suppress the seizure. Especially if the contractions take more than 5 minutes. Examples of such medication is midazolam (nasal spray) and diazepam (rectal administration). Midazolam nasal spray is the easiest to use and is therefore prescribed more frequently. If the muscular contractions continue more than 5 minutes, one spray of midazolam (2,5mg) should be administered to each nostril, with a total dose of 5mg.

Epilepsy medication in case of inability to swallow

As a result of decreased consciousness or neurological deficits a patient can lose the ability to swallow. In this case, an IV might not be an option. Nonetheless, it is still advisable and desirable to continue the treatment of (possible) seizures. Options in this case, are diazepam via the anus or clonazepam via the mouth. Discuss this with your doctor.

Headache

A brain tumor could cause headaches, but this is not always the case. Headaches can have different causes, such as an adverse effect of medication. For this reason, it is advisable to always discuss these complaints with your doctor. If the brain tumor is the (main) cause of the headache, the best suitable treatment is (an increase in the dose of) dexamethasone. Regular painkillers are also effective. Usually, the first step is advising paracetamol, with a maximum dose of 1000mg four times per day (total daily dose 4000 mg). If paracetamol is not sufficient, do not wait too long. Discuss this with your doctor. In case of an extreme headache, it is advised to switch to morphine. Examples of morphine are oxycodone and fentanyl patches. Less strong opioids (such as tramadol and codeine) are not as effective for severe headaches, and therefore should be avoided.

Nausea and vomiting

High intracranial pressure (meaning high pressure in the head) can cause nausea and vomiting. These symptoms can also have other causes, such as a side effect of medication. Always discuss nausea and vomiting with your treating physician.

Nausea and/or vomiting as a result of a brain tumor is treated most effectively with dexamethasone. Other medication might be necessary if (a rise in the dose of) dexamethasone is not expected to be sufficient. In these situations, your doctor might prescribe medication such as metoclopramide.

Decreased consciousness/drowsiness

A brain tumor can cause a rise in intracranial pressure. This can result in a decreased consciousness or drowsiness. However, there are more possible causes of decreased consciousness in the end-of-

life phase, such as side effects of medication or dehydration. Epilepsy is another cause, and does not always go hand in hand with visible seizures. Always discuss a reduces level on consciousness with your doctor.

Poor sleep / insomnia

There are many causes of poor sleep in the end-of-life phase. Therefore, you should discuss this with your doctor. In case of a worsening confused state, nightmares, distraction and/or hallucinations, contact your doctor as soon as possible. In case of poor sleep, it is important to keep someone awake during the day. Dexamethasone can also cause insomnia. For this reason, it can be useful to take dexamethasone in the morning. Sometimes, a sleeping draft is necessary, but this is only temporarily effective.

Incontinence

Continence is regulated by the brain. In case of a brain tumor, it is possible for patients to experience problems concerning continence. Incontinence for defecation is very rare. It is impossible to rule out other possible causes, such as a urinary tract infection. Discuss these symptoms with your treating physician. Sometimes, this can be treated with medication. However, in most cases, incontinence pads are the only option. For some patients, a catheter is useful.

Advises for incontinence:

Frequently visit the toilet, every 2-3 hours, also if you do not feel the urge.

If necessary, set an alarm during the night.

Grant enough peace and privacy during urination.

Make sure the toilet, toilet chair or urinal are easily accessible.

Offer good foot support while urinating.

Make adjustments to the toilet if necessary, such as lifting the seat.

Avoid diuretics (also called water pills), coffee and alcohol.

Pay attention to skin care: wash four times each day with lukewarm water. Pat the skin dry, do not use talcum powder, zinc cream can be useful.

Use incontinence pads, making sure the skin is as dry as possible.