

Watch and wait

When you are diagnosed with a brain tumour, you may expect to receive immediate treatment, involving neurosurgery to remove all or part of the tumour, and/or radiotherapy and chemotherapy. However, with some low grade, slow growing tumours that are unlikely to spread, a 'watch and wait' treatment strategy is sometimes used.

Taking a 'watch and wait' approach means closely monitoring your condition without giving any treatment until symptoms develop or worsen, or your scan changes.

This fact sheet explains when and why this is sometimes more appropriate than immediate intervention and also looks at the emotional impact of receiving this type of treatment.

In this fact sheet:

- Which tumour types might receive watch and wait treatment?
- When is watch and wait used?
- How does watch and wait work?
- Emotional aspects
- Answers to some common questions that you may have about watch and wait

What types of tumours may receive a 'watch and wait' approach?

The most common types of brain tumours to receive a watch and wait approach are newly diagnosed low grade gliomas (grade 1 or grade 2 astrocytomas, grade 2 oligodendrogliomas) and grade 1 meningiomas.

Why is 'watch and wait' used?

These low grade tumours are typically slow growing, unlikely to spread and may not cause any, or cause only a few symptoms for many years. Examples would be tumours that were discovered 'by accident' - perhaps a scan was given for a head injury (you may hear this referred to as an 'incidental finding'); or tumours in which the only symptoms are seizures that are being well-controlled by anti-convulsants (anti-epilepsy drugs) or are symptoms that you feel able to live with without them badly affecting your quality of life.

'Watch and wait' may also be used when a tumour is growing in an area that is very difficult to operate on. In this case, the possible treatments, such as neurosurgery, could have a greater risk of causing harm to the brain than not doing anything. This is particularly the case if the tumour is in or near an important part of the brain, such as those involved in memory or speech. The balance as to whether to treat or not can sometimes be a difficult decision that you, as the patient, should be involved in.

'Watch and wait' would also be used if you did not want to have surgery or other treatments - for whatever reason. It is also sometimes used after initial treatment, such as biopsy or debulking surgery (partial removal of the tumour).

How does 'watch and wait' work?

The use of 'watch and wait' has been made possible by the development of MRI (Magnetic Resonance Imaging) scans. This type of scanning means that, with good accuracy, the size and features of a tumour can be monitored and compared over time. Their advantage over other types of scans previously used (CT scans) is that frequent scans can be given without exposing you to repeated doses of radiation.

If you are put on a 'watch and wait' approach, you will see your specialist for regular check-ups/scans, which could be in 3, 6 or 12 monthly intervals, and treatment is only begun if:

- There is a marked increase in tumour size
- You develop symptoms, or worsening of symptoms, that are badly affecting your quality of life e.g. uncontrollable seizures
- The tumour becomes a higher grade (depending on your tumour and age, this could take many years or not happen at all)

(Brain tumours are graded 1-4 according to their behaviour, such as the speed at which they are growing. Grades 1 and 2 are low grade, slow growing and sometimes referred to as 'benign', though this term is less used nowadays as low grade brain tumours can still be serious. They can cause harm by pressing on and damaging nearby areas of the brain or blocking the flow of the cerebrospinal fluid causing a build-up of pressure in the brain. Grades 3 and 4 are high grade, fast growing and often referred to as malignant. Tumours behaviour can sometimes change i.e. they can start to grow faster and therefore become a higher grade.)

What is the evidence for 'watch and wait'?

In terms of overall survival, the evidence for 'watch and wait' versus immediate intervention is slightly mixed. Many older studies have suggested that deferring treatment does not make the outcome worse in patients with low grade gliomas (low grade astrocytomas); nor does it affect cognitive (mental) performance or quality of life.

However, a more recent study has suggested that, for some patients with certain low grade gliomas (low grade astrocytomas and maybe low grade oligodendrogliomas), early surgery to remove a large proportion of the tumour may lead to better overall survival than watch and wait. The evidence, however, is not completely clear, as there were more people with tumours that have a better prognosis (overall survival) i.e. oligodendrogliomas, in the early surgery group than there were in the watch and wait group. This could have weighted (biased) the result in favour of early surgery. It is important

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to remember that, whilst these results supported the idea that early surgery could be the best treatment for some patients (specifically patients with low grade astrocytomas), the suitability of such an approach will depend on the patient and the characteristics of their individual tumour. There is also insufficient data about other low grade tumours. Your treatment will be tailored individually to your needs. If you have any questions or concerns, speak to your health team.

Emotional impact of 'watch and wait'

Being told that you have a brain tumour, but no active treatment will be given until it grows bigger, or it becomes more aggressive or you have more symptoms, can be a devastating blow and a very frightening time. The time between appointments with your health team can also seem, or be, long, leaving you feeling cut adrift and isolated. You may also have various symptoms to deal with, such as seizures, which can affect your quality of life, for you and your family. These effects can be direct or indirect e.g. you may no longer be able to drive.

However, it can help if you are able to focus these feelings into learning more about your tumour and the support that is available, so you feel more in control.

This watch & wait time can give you the opportunity to discover all the available options before you have to make any decisions about how you want your treatment to proceed and also to learn about the latest research and what it recommends. It gives you the time to talk to your family about risks and benefits and to talk to others on a watch and wait approach, who can share their thoughts and experiences.

Other things you may wish to do to help you feel more in control include asking your health team for advice about when you should contact a health professional with regards to new or changing symptoms, and also which symptoms can be dealt with by your GP and which the hospital needs to know about. The Brain Tumour Charity's *Symptoms of a brain tumour in adults* fact sheet can also help with this.

Also ask how far apart your appointments will be, so you know what to expect, and whether there is a named contact e.g. a Clinical Nurse Specialist (CNS), key worker or a regularly monitored email address, whom you can contact if you have concerns between times.

Keep your own file of every appointment and what was discussed, all test results and particularly a copy of every scan. This can be useful if dealing with different specialists, so you can pass on the information to the correct people when needed.

Some people also feel more secure by wearing a medic-alert bracelet in case of accidents or if they have a seizure or worsening of seizures. That way anyone attending to you will know you have a brain tumour.

It is important to be aware that different hospitals will have different procedures and services. It may be that your hospital does not have a CNS or you may see your consultant only once a year (though you can always ask to see them between scheduled appointments). This can leave you feeling isolated. Speaking to others in the same situation can help.

The Brain Tumour Charity has an active Facebook support group that you can access anywhere in the world, where you can 'meet' other brain tumour patients and carers and discuss your worries, fears and share ideas.
<https://www.facebook.com/groups/114009085471466/>

We also have a network of local support groups and telephone support groups, where you can talk with others and ask some of the questions about living on a 'watch and wait' approach that healthcare professionals may not be able to answer.

We also have our Support & Info Line - if you need information, details of the support groups or other services, or just want to talk, please call our Support and Information Team on 0808 800 0004 or email support@thebraintumourcharity.org

Whatever you decide to do with the time, it is important that this is a choice that is best for you and that you fully understand why this approach has been taken. Your health team are available to answer questions specific to your case and you should speak to them if you are worried about the decision taken, or if you feel there are any changes in your symptoms.

Getting a second opinion

If you are uncertain about the decision, even after talking to your health team, you can ask your consultant or health team for a second or further opinion, either on the NHS or privately.

Although there is not a legal right to have a second opinion, a health professional will rarely refuse to refer you for one. Healthcare professionals are used to being asked about

a second opinion - they will not be offended, nor will your care be affected.

The possible advantages of a second opinion are, if both doctors are in agreement, you will feel more confident about their decision.

The possible disadvantages are that any treatment they may suggest will be delayed while you wait to see the other consultant and your information is transferred; you may find it upsetting if you are told the same; or you may find it difficult to decide which treatment to have if they suggest a different treatment. Having a second opinion does not mean the other doctor will automatically take over your care. If you want to be treated by the new consultant, this will need to be arranged with the doctors and hospitals, but may involve extra travel and costs.

If you are having difficulty getting referred for a second opinion you can call our Support & Info Line on 0808 800 0004. The Patient Advice and Liaison Service (PALS) in your hospital or your local citizens' advice service (CAB) may also be able to offer advice.

Resources

The following are some resources that you may find helpful if you have a low grade tumour and have been put on watch and wait approach.

Live panel discussion on low grade brain tumours

<http://www.thebraintumourcharity.org/support-information/live-panel-low-grade-brain-tumours>

Brain Tumours: Living Low Grade - a book by Gideon Burrows.

Features personal testimonies from those dealing day-to-day with the impact of their tumours, as well as information, support and reassurance for those with a low grade brain tumour, their family and friends

<http://www.thebraintumourcharity.org/support-information/Support/support-library>

