

Watch and wait(active monitoring)

When you're diagnosed with a brain tumour, you may expect to have immediate treatment, possibly involving surgery and/or radiotherapy and chemotherapy. However, with some low grade, slow-growing tumours, a watch and wait treatment strategy is sometimes used.

Taking a watch and wait approach means actively monitoring your condition, but without giving any immediate treatment.

This can feel quite alarming.

This fact sheet explains when and why watch and wait is sometimes more appropriate than immediate intervention. It also looks at how to deal with the emotional impact of receiving this type of treatment.

In this fact sheet:

- What is watch and wait?
- Am I likely to have watch and wait treatment?
- When and why is watch and wait used?
- Coping with watch and wait
- Answers to some commonly asked questions you may have about watch and wait

What is watch and wait?

Traditionally called watch and wait, this form of treatment is more accurately described as active monitoring. You may hear it called this by your health team.

If you're put on a watch and wait approach, you won't have immediate treatment, but you will see your specialist for regular check-ups, including scans.

These appointments could be every 3, 6 or 12 months. Further treatment is only begun if:

- there's a marked increase in the size of your tumour
- you develop symptoms, or a worsening of symptoms, that badly affect your quality of life, e.g. uncontrollable seizures
- your tumour becomes a higher grade (starts growing more quickly)
 - depending on your tumour and age, this could take many years, or not happen at all.

The scans you have will be MRI (Magnetic Resonance Imaging) scans. This type of scan means that the size and features of your tumour can be very accurately monitored and compared over time.

They also mean you can have regular scans without exposing you to frequent doses of radiation that having repeated CT (Computerised Tomography) scans would cause.

For more information on these scans, see the [Scans for adults with brain tumours](#) webpage and fact sheet.

Am I likely to have watch and wait treatment?

The most common types of brain tumours to have a watch and wait approach are newly diagnosed low grade brain tumours, known as gliomas. In particular, gliomas called grade 1 or grade 2 astrocytomas, grade 2 oligodendrogliomas and grade 1 meningiomas.

For more information about these brain tumour types, see our webpage [Adult brain tumour types](#).

What does low grade mean?

Brain tumours are graded 1-4 according to what they look like and their behaviour, such as the speed at which they grow. Low grade tumours are graded 1 or 2.

Low grade tumours:

- are slow growing
- have relatively well-defined edges
- are unlikely to spread to other parts of the brain
- are less likely to return (if they can be completely removed).

They're sometimes still referred to as 'benign', but this term can be misleading. Low grade brain tumours can still be serious.

When and why is watch and wait used?

Watch and wait is typically used for low grade tumours in the following situations:

- Tumours that may cause no, or only a few, symptoms for many years.

Examples of such tumours would be:

- those discovered by accident - perhaps when a scan was given to investigate a head injury
 - you may hear this referred to as an incidental finding
 - tumours in which the only symptoms are seizures that are being well-controlled by anti-convulsants (anti-epilepsy drugs)
 - tumours whose symptoms you feel able to live with, without them badly affecting your quality of life.
- Tumours growing in an area that's 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.

- If you didn't want to have surgery or other treatments - for whatever reason.
- After initial treatment, such as biopsy or debulking surgery (partial removal of the tumour).

Being on watch and wait can be scary - how do I deal with this?

It can be devastating and frightening to be told that you have a brain tumour, but that no active treatment will be given until it grows bigger, it becomes more aggressive or you have more symptoms.

The time between appointments with your health team can also seem (or be) long, leaving you feeling adrift and isolated.

You may also have various symptoms to deal with, such as seizures, which can affect 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.

People who have been in this situation have told us about what they have found to help. These include:

Learn about your tumour, the treatment and support available

If you're able to focus your feelings into learning more about your tumour and the support that's available, it can make you feel more in control.

This watch and wait time can give you the opportunity to discover all the available options before you have to make any decisions about your treatment and also to learn about the latest research and what it recommends.

Talk to your family

Watch and wait 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.

Talk to your health team

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. You can also ask them which symptoms can be dealt with by your GP and which the hospital needs to know about.

Our [Symptoms of a brain tumour in adults](#) webpage and fact sheet can also help with this.

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

Our [Questions to ask](#) webpage can help with other questions to ask.

It's important to be aware that different hospitals will have different procedures and services.

It may be that your hospital doesn't 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.

Speak to others in the same situation

The Brain Tumour Charity has several active closed Facebook support groups 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.

bit.ly/FBSupportGroups

We also have telephone support groups and a database of local support groups that we can signpost you to. At these groups you can talk with others and ask some of the practical questions about living on a watch and wait approach that healthcare professionals may not be able to answer.

We also have our Information and Support Line - if you need information, details of the support groups or other services, or just want to talk, please call our Information and Support Team on 0808 800 0004, email **support@thebraintumourcharity.org** or get in touch with us online via **thebraintumourcharity.org/live-chat**

Medic-alert bracelets

Some people feel more secure wearing a medical 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.

Keep a record

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 you're dealing with different specialists, so you can pass on the information to the correct people when needed.

Whatever you decide to do with the time

It's 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're worried about the decision taken, or if you feel there are any changes in your symptoms.

Getting a second opinion

If you're uncertain about the decision to put you on watch and wait, 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 isn't 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 won't be offended, nor will your care be affected.

The possible advantages of a second opinion arise that, if both doctors are in agreement, you'll 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 thing
- 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're having difficulty getting referred for a second opinion, you can call our Information and Support Team on 0808 800 0004, email support@thebraintumourcharity.org or get in touch with us online via thebraintumourcharity.org/live-chat

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

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

Recording of live panel discussion on low grade brain tumours

Our live panel discussions deal with topics that affect the brain tumour community. They allow people to hear different viewpoints providing detailed information, practical tips and informed opinion. People were able to submit questions beforehand and receive answers on the night from the expert panel. Recordings of this and other live discussions can be found on our website:

thebraintumourcharity.org/get-support/online-support/live-discussions

Brain Tumours - Living Low Grade: the patient guide to life with a slow growing brain tumour

Gideon Burrows, 2013.

A readable and moving non-technical guide about living with a low grade tumour. This book 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.

thebraintumourcharity.org/understanding-brain/tumours/resources/books

What if I have further questions or need other support?

You can contact our Information and Support Team in the following ways:

- Call 0808 800 0004 (free from landlines and most mobiles including 3, O2, EE, Virgin and Vodafone)
- Email: support@thebraintumourcharity.org
- Live Chat: Get in touch with us online via thebraintumourcharity.org/live-chat
- Join one or more of our closed Facebook groups: bit.ly/FBSupportGroups
- Website: thebraintumourcharity.org/getsupport

Disclaimer

This resource contains information and general advice. It should not be used as a substitute for personalised advice from a qualified specialist professional. We strive to make sure that the content is accurate and up-to-date, but information can change over time.

Patients must seek advice from their medical teams before beginning or refraining from taking any medication or treatment.

The Brain Tumour Charity does not accept any liability to any person arising from the use of this resource.

About this information resource

The Brain Tumour Charity is proud to have been certified as a provider of high quality health and social care information by The Information Standard – an NHS standard that allows the public to identify reliable and trustworthy sources of information.

Written and edited by our Information and Support Team, the accuracy of medical information in this resource has been verified by leading health professionals specialising in neuro-oncology.

Our information resources have been produced with the assistance of patient and carer representatives and up-to-date, reliable sources of evidence.

We hope that this information will complement the medical advice you have already been given. Please do continue to talk to your medical team if you are worried about any medical issues.

If you would like a list of references for any of our information resources, or would like more information about how we produce them, please contact us.

We welcome your comments on this information resource, so we can improve. Please give us your feedback via our Information and Support Team on **0808 800 0004** or support@thebraintumourcharity.org

About us

The Brain Tumour Charity is at the forefront of the fight to defeat brain tumours and is the only national charity making a difference every day to the lives of people with a brain tumour and their families. We fund pioneering research worldwide, raise awareness of the symptoms and effects of brain tumours and provide support for everyone affected to improve quality of life.

We wouldn't be able to make the progress we have without the incredible input we receive from you, our community.

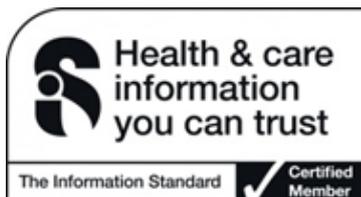
Whether it's reviewing our information resources, campaigning for change, reviewing research proposals or attending cheque presentations, everything you do helps to make the difference.

To find out more about the different ways you can get involved, please visit thebraintumourcharity.org/volunteering

We rely 100% on charitable donations to fund our vital work. If you would like to make a donation, or want to find out about other ways to support us including leaving a gift in your will or fundraising through an event, please get in touch: Visit thebraintumourcharity.org/get-involved, call us on 01252 749043 or email fundraising@thebraintumourcharity.org

Watch & wait (active monitoring)

Your notes



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