

PATIENT GUIDE TO BRAIN TUMOUR TREATMENT AND SERVICES

For adults

thebraintumourcharity.org

Finding out that you have a brain tumour is a frightening and overwhelming experience for anyone. You may feel as though your whole world has been turned upside down.

We're here for you

To help guide you through the system. To answer your questions. To help you know you're not alone.

There are some basic aspects of care that we think everyone should expect when they're diagnosed with a brain tumour. We've outlined them in this guide as it is important to know what you should expect from the health professionals who are looking after you.

We've helped thousands of people who have been in exactly your position. People living with a brain tumour are at the heart of everything we do. We want to make sure that you get the best treatment and care possible.



We recommend that you read this booklet alongside our specific information about the type of brain tumour you have. All of our information is also available online at thebraintumourcharity.org/understanding-brain-tumours

If you'd like to discuss this information, call The Brain Tumour Charity Support & Info Line free on 0808 800 0004, Monday–Friday, 9.00am–5.00pm.

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A brain tumour diagnosis can be overwhelming, we're here to make it as simple and easy to cope with as possible.

Your right to know

Here you'll find information on how to access the NHS services and the standards of care you should expect.

Related content

Our related content gives you a bit more information about some of the things you'll read about in this guide.

Resources

We've put together a list of other helpful resources that you may find useful which take you through each topic step-by-step.

Watch

Our case study videos can help you feel less alone by hearing from others in a similar situation.

Jargon buster

The jargon buster will help explain complex medical terms (highlighted in bold) that you may not have come across before.

Foreword



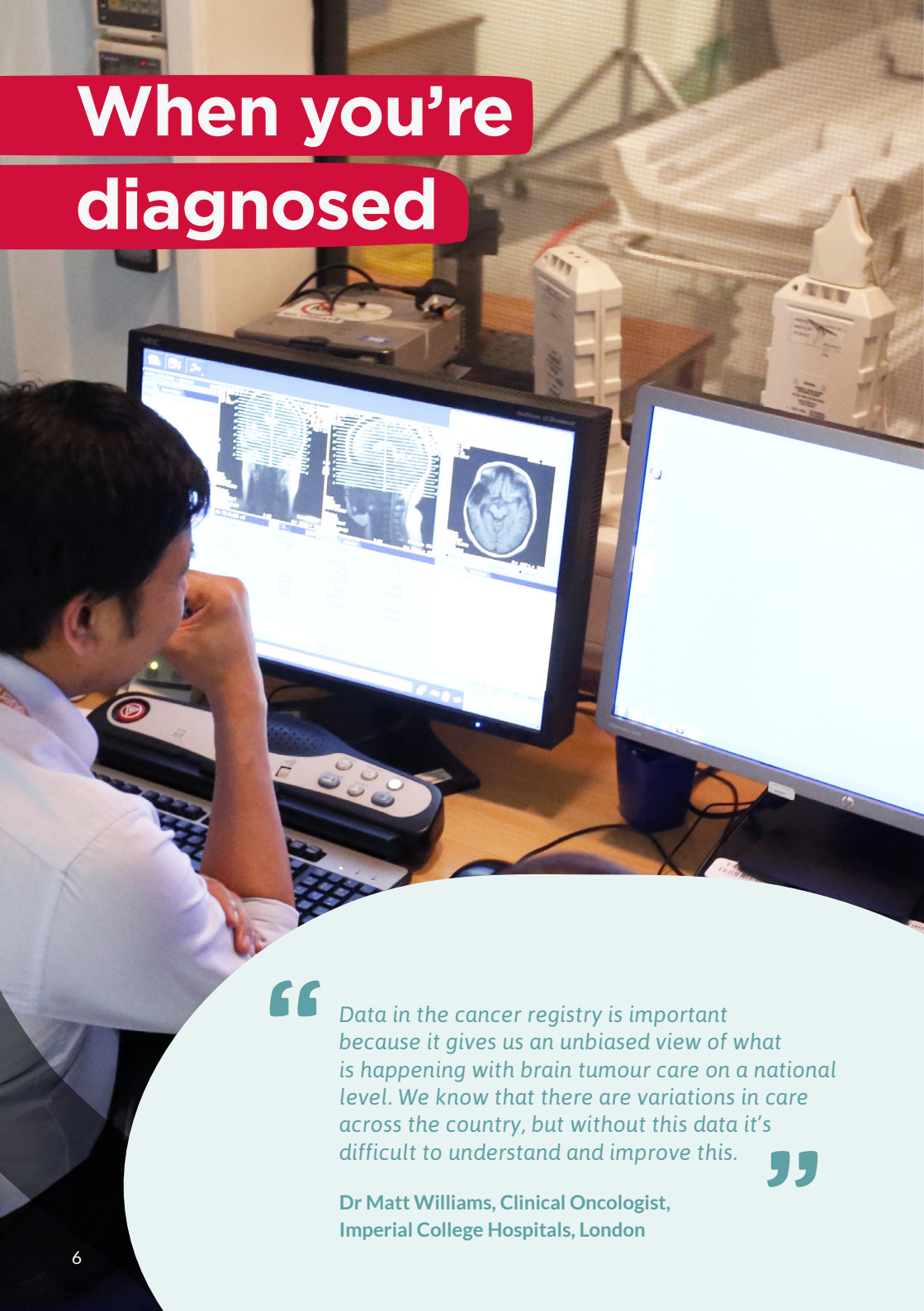
As a neurosurgeon, I see first-hand the bewilderment that people experience when they are diagnosed with a brain tumour. That diagnosis starts them and their families on an unexpected journey where they must navigate the system, make choices about treatments and try to adjust their lives around this condition. This guide clearly and simply states the minimum standards of care which should be provided by the NHS, as well as some more innovative and research focussed steps.

I believe that this will prove invaluable to anyone who is newly diagnosed as well as those who are further along their journey. It will help them understand what lies ahead and empower them to ask for these minimum standards to be followed. Being diagnosed with a brain tumour can feel very isolating but The Brain Tumour Charity can provide information and support each step of the way, travelling with you, so you are not alone.

Colin Watts

Neurosurgeon, Addenbrooke's Hospital, Cambridge,
Steering Group Chair

When you're diagnosed



“Data in the cancer registry is important because it gives us an unbiased view of what is happening with brain tumour care on a national level. We know that there are variations in care across the country, but without this data it's difficult to understand and improve this.”

Dr Matt Williams, Clinical Oncologist,
Imperial College Hospitals, London

Your right to know

Being given the right information is important for you and your family. It will help you to make sense of what you've been told and help prepare you for the next stages in your treatment or care.

- ✓ When you receive the diagnosis of a brain tumour, it should be communicated to you face to face, sensitively and in a private space – it's okay to ask if there is somewhere more private that you and your family can be when you are talking to a doctor or nurse at any time.
- ✓ If you want family or friends with you, then you should be able to have them there.
- ✓ You should be given time to ask questions and not feel rushed – it's a lot to take in. Take time out to write down any questions before your appointment so that you get all the answers you need. There really is no such thing as a silly question.
- ✓ You should be given information and details of local support services – if you're not, then do ask. There may be support available in your area that you're not aware of.
- ✓ You should be given information to take away about your tumour type and the possible long-term effects it may have. We know how difficult it is to remember what you've been told and it's even harder to take it all in one go.
- ✓ You have the right to ask for a second opinion about your diagnosis and treatment, so don't be afraid to ask if you have any concerns about what you've been told.
- ✓ You should be made aware that your health data is recorded and used to monitor how many brain tumour diagnoses are made each year and what treatments are used. We believe it's really important that this data is collected as it helps us understand the bigger picture of brain tumours across the whole country, but you should be told how it's used.
- ✓ You should be given the name and contact details of a keyworker who can answer any questions about your diagnosis and the next steps. This is usually a **clinical nurse specialist** who is experienced in supporting people with brain tumours and will play a key role in the coming weeks and months. Remember to keep their details to hand.

If you haven't been given or told any of these things, then please do ask a member of your healthcare team.

Related content

Biomarker testing

Biomarker testing involves taking a small amount of tumour and analysing the biology of it. It can help make sure you get an accurate diagnosis and that your **treatment plan** is tailored to your particular tumour type.

We believe that this type of testing should be available to everyone – so make sure that you ask if it hasn't been offered. There may be good reason why it isn't appropriate for you, but your doctor will be able to explain this.

Watch

Living with a brain tumour

thebraintumourcharity.org/living-with-a-brain-tumour



Resources

Getting a diagnosis
thebraintumourcharity.org/diagnosis

Biomarkers
thebraintumourcharity.org/biomarkers

The Cancer Registry
thebraintumourcharity.org/the-cancer-registry

Getting a second opinion
thebraintumourcharity.org/second-opinion

During your treatment

“As Clinical Nurse Specialist we are the lynchpin in the patients pathway. We offer vital support, information and signposting as well as sound clinical advice. We liaise with community services and primary care teams and help coordinate the multifaceted care our complex brain tumour patients need and require. We are experts within our field. We are patient advocates and have a duty of care towards them and their families.”

Ingela Oberg, Clinical Nurse Specialist,
Addenbrooke's Hospital, Cambridge

Following a diagnosis you may face complex decisions about your treatment.

A **multidisciplinary team** (often referred to as the MDT), made up of a broad section of healthcare professionals with specialist knowledge and experience of brain tumours, will make recommendations about the best treatment for you. All the options should be discussed with you and

your family so that you can make informed decisions about your care. Throughout your treatment, your progress will be monitored.

As brain tumours affect the part of your body that controls all of your functions and makes you who you are, the tumour itself or the treatment that you receive may have an impact on your skills and abilities.

Your right to know

- ✓ You can access **holistic needs assessment**, to monitor your support needs before you're discharged from hospital so that the right help is available to you.
- ✓ A written personalised care plan – about how your treatment and care should be carried out.
- ✓ Information about the treatment options that have been recommended, including any possible side effects or associated risks.
- ✓ An opportunity to raise any questions with your keyworker or someone from your health team.
- ✓ The details about who you can contact out-of-hours if you have any concerns, or in the event of an emergency.
- ✓ You have the right to ask for a second opinion about your diagnosis and treatment, so don't be afraid to ask if you have any concerns about what you've been told.
- ✓ The opportunity to participate in clinical trials or other available research opportunities.

We're here to help

If you don't believe that this is something that you are currently being offered then please contact our Information & Support Team who can work with you to help you access your rights as quickly as possible.

Related content

Neurosurgery for glioma

If you have been diagnosed with a radiologically suspected high grade **glioma** (glioblastoma – GBM) and surgery to remove the tumour has been recommended, then ask your doctor about ‘the pink drink’.

In many areas of the UK, patients can be given a pink drink just before surgery (it’s actually a drug called 5-ALA) that’s absorbed only by tumour cells and makes them ‘glow’ under a special microscope and light used during surgery. This means that your surgeon can see more clearly where

the tumour tissue is in order to remove it. More accurate removal of the tumour means that the healthy brain tissue surrounding the tumour can be avoided and therefore the risk of surgery damaging healthy brain is reduced. Unfortunately this isn’t routinely offered everywhere, but it should be. Neurosurgeons across the UK have been trained and most have the equipment that is needed. With the power of patients we could ensure that it’s available for everyone who needs it.

Clinical trials and research

Because brain tumours are rare, it is important that everyone who receives a diagnosis is given the opportunity to take part in **clinical trials** and research. Often this will mean that you’ll have access to new treatments. It’ll also ensure that we learn from every case and make progress in research that seeks to find better treatments or improve quality of life.

Biobanking is also a good way of contributing to research. If you’re having surgery to remove a tumour or a biopsy to take a sample of the tumour, then

excess tissue can be taken, stored and used in research to enhance our understanding brain tumours. Make sure that you have been asked to sign a consent form before surgery so that this can happen.

With your help we can make progress and improve life for those with a brain tumour today and in the future.

Precision medicine – genome sequencing

Our DNA is unique to us and is the blueprint for making us who we are. Our DNA contains all our genes. By using a laboratory technique called genome sequencing we can find out the causes of diseases and even find clues about possible ways to treat them, including brain tumours.

We’re living in a world where advances in science and medicine are happening very quickly. As we understand more about brain tumours and how different genetic make-ups respond to different treatments, we move further away from a one size fits all approach. The ‘100,000 Genomes’ project in the UK is moving us closer to finding better ways to treat brain tumours.



“When 5-ALA is used in surgery for glioblastoma fewer cancer cells are left behind. Ensuring that as much of the tumour is removed as possible is the only factor we can influence when it comes to improving survival”

Mr Stephen Price,
Neurosurgeon,
Addenbrooke's Hospital,
Cambridge



"Being able to understand the biology and genetic make-up of brain tumours is vital for not only planning treatment for those who have been diagnosed with a tumour today, but it is essential to enhance our knowledge so that better, more targeted treatments can be developed for the future."

Prof Keyoumars Ashkan,
Neurosurgeon, King's
College Hospital

Watch

Understanding clinical trials
thebraintumourcharity.org/clinical-trials



Resources

The multi-disciplinary team factsheet
thebraintumourcharity.org/mdt-factsheet

The multi-disciplinary team
thebraintumourcharity.org/your-mdt

Adult treatments for brain tumours
thebraintumourcharity.org/adult-treatments

Campaign with us
thebraintumourcharity.org/help-make-this-change

Clinical trials database
thebraintumourcharity.org/clinical-trials-database

Accelerate
thebraintumourcharity.org/accelerating-progress

Genomics England
genomicsengland.co.uk

After your treatment



“After you come off treatment, people often tell us that they feel like they are falling off a cliff. Suddenly the support you have had throughout from clinicians is gone and you are left to fend for yourself. Accessing your key worker, that you are entitled to, and other services such as ours, can act as a lifeline and provide you with the care and support you need.”

Cameron,
Information & Support Services Manager

It's often when treatment finishes or you're discharged from hospital following surgery that you can feel very alone and overwhelmed. You may still be coming to terms with the diagnosis and the changes that it has brought – whether to you personally, or to the relationships with those around you.

Your right to know

- ✓ Make sure that you have the contact details of your keyworker – they will be able to help you access support and **rehabilitation** services if you need them.
- ✓ It's natural to experience periods of low mood when you've been through all that you have, but there may be times when some support is needed through counselling or other support services – your family may need this support too. It really is okay to ask for help.



Related content

Watch and wait

For some types of brain tumour, treatment may not be necessary or needed straight away and the tumour will be monitored on a 'watch and wait' programme. Although this may be good news, it can feel incredibly frustrating and you may feel like you are just being left to cope on your own.

The right support

Getting the right support for any difficulties you may have is very important. Your health team will be able to refer you to any of these services or you can request a referral from your GP.

- If you're affected by epilepsy, ask to be referred to a neurologist as they are the best person to support in the treatment and management of seizures. You can also ask to see an epilepsy nurse specialist who can provide advice when needed.
- If you're struggling to communicate, have difficulty getting the right words out or are finding it difficult to follow conversations, a speech and language therapist can provide help and strategies to cope with these difficulties.
- If you're having any mobility difficulties, a physiotherapist can work with you to find techniques to support you or give you exercises to restore function.
- If you're experiencing fatigue or having difficulties with activities of daily living or personal care, an occupational therapist can work with you to provide strategies and practical solutions to help you maintain, regain or improve your skills.
- If you're experiencing any visual difficulties, you should be referred to an eye specialist for further assessment.
- If you're experiencing memory or **cognitive** difficulties, a neuropsychologist will be able to assess the nature and extent of any problems and suggest techniques to help you manage.

Watch

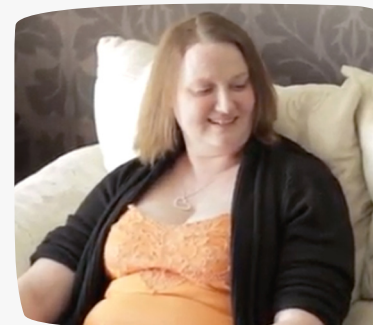
Fatigue and brain tumours

thebraintumourcharity.org/fatigue



Memory difficulties and brain tumours

thebraintumourcharity.org/memory-difficulties



Resources

Watch and wait
thebraintumourcharity.org/watch-and-wait

Epilepsy (seizures) and brain tumours
thebraintumourcharity.org/epilepsy

Communication difficulties
thebraintumourcharity.org/communication-difficulties

Fatigue and brain tumours
thebraintumourcharity.org/fatigue

Memory difficulties and brain tumours
thebraintumourcharity.org/memory-difficulties

Supportive and palliative care



“When it comes to accessing help from support services I always tell people to take it. Whether it's psychological help, physiotherapy or even access to work schemes, absolutely take it.”

James from Cheshire

We know that hearing words such as 'palliative care' can be very distressing and it may be something that you associate with end of life. Palliative care is actually the treatment of symptoms for a complex illness and is available from the point of diagnosis.

But what it really means is that your care is coordinated by professionals with the right knowledge and experience to manage the symptoms and side effects of your

treatment. They will also support you and your family with some of the practical and emotional worries and concerns that are often associated with a serious illness.

Planning for an uncertain future is undoubtedly going to be tough for you and your loved ones, but it's important and can help you live the life you want to live.



Your right to know

- ✓ Your team should provide you with information about palliative care services in your area.
- ✓ Those services will then be able to tell you about the ways in which they can help you and your family.
- ✓ Provide with help and advice around planning your care if your symptoms worsen or you find you need extra help.
- ✓ Help to write down the things that are important to you, including information on making advance decisions around your treatment and care (known as 'advance directives' or 'advance care planning').



Resources

Mariecurie
mariecurie.org.uk/help

National Council for Palliative Care
ncpc.org.uk

Hospice UK
hospiceuk.org

How we can support you

We're here for you. Whether you've recently been diagnosed, or have been living with a brain tumour for some time. We're also here for your family and friends.

You can come to us for information or support – we work with world leading experts to make sure that our information is up to date, reliable and trustworthy. Our Support & Info Line can offer you a listening ear if you want some emotional support, or can answer your questions.

If they don't know the answer, then they will carry out research for you – whether that's finding suitable clinical trials or information on a particular treatment. We also offer expert advice on benefits through our partnership with our

local Citizen's Advice and are constantly developing resources that are here to help you with everyday life.

If you're feeling alone, then why not join one of our online communities? Our closed Facebook groups offer friendly support from others who have similar experiences. To join our Facebook group please visit [thebraintumourcharity.org/facebook-support](https://www.thebraintumourcharity.org/facebook-support)

And if you want to make a difference, you're welcome to join our community of people who are supporting research and campaigning to make sure that brain tumours get the attention they need so that services are improved and everyone affected gets access to the best treatment and care possible.



Checklist

We know how easy it is to feel overwhelmed and forget to ask your doctor or health team questions when you see them, so we've put together this checklist to help you get the very best treatment and care.

Have you been given:

- ✓ Name and contact details of a keyworker (usually a clinical nurse specialist).
- ✓ Information about your specific tumour type and the possible long term effects it may have.
- ✓ Time to ask questions.
- ✓ The opportunity to discuss the treatment options available to you.
- ✓ Information about the treatment you have been recommended, including any possible side effects or associated risks.
- ✓ Details of who you can contact out-of-hours if you have any concerns, or in the event of an emergency.
- ✓ Information about local support services.
- ✓ The opportunity to talk about palliative care services in your area.

Have you been told about:

- ✓ How your data (information about you, your diagnosis and treatment) is being collected and used.
- ✓ Clinical trials that are available to you.

Have you talked with your doctor about whether:

- ✓ Biomarker testing is appropriate and available to you?
- ✓ The pink drink (also known as 5-ALA) is appropriate for surgery (only for suspected high grade gliomas).
- ✓ You can have your genome sequenced as part of the 100,000 Genomes Project?

Have you had:

- ✓ A Holistic Needs Assessment to see what support you will need.
- ✓ An individual care plan so that you know what is planned and how your care will be carried out.

Don't forget that we are here to support you too.

You can find out more about all our services on our website or by contacting our Support & Info Line on 0808 800 0004 or by emailing support@thebraintumourcharity.org

A close-up photograph of a woman and her young daughter lying in grass. The woman has long dark hair and is smiling warmly at the camera. The daughter, with blonde hair, is also smiling and looking towards the camera. They are both wearing casual clothing. The background is a soft-focus green, suggesting an outdoor setting.

About us

“The support we received from The Brain Tumour Charity after Madeleine’s diagnosis has made a huge difference to our lives. They understood what we were going through and helped us practically and emotionally, so that we feel much more confident about the future.”

Fiona’s ten-year-old daughter Madeleine was diagnosed with an epidermoid cyst in her brain.

We fund it all

Since 1996 we have been at the forefront of the fight against brain tumours. We know how vital it is to find a cure. Laboratory-based research is essential, but on its own is not enough. That’s why we fund every phase of research.

We work

with researchers to find the cause of brain tumours, to diagnose the disease more accurately and to understand what prevents early diagnosis.

We investigate

new ways to find a cure and support clinical trials to improve treatment and care.

We collaborate

with leading researchers across the world, as well as Cancer Research UK, to ensure we maximise all opportunities.

Alongside research, we do everything we can to improve life for those affected.

We help

people affected by a brain tumour every day through our Support & Information Service.

We campaign

for early and accurate diagnosis. Our HeadSmart campaign has halved the average diagnosis time for childhood brain tumours in the UK.

Our impact to date:



3. HeadSmart was developed in collaboration with the Children's Brain Tumour Research Centre at The University of Nottingham and the Royal College of Paediatrics and Child Health.

Jargon Buster

Biobanking

The process of collecting and storing body fluids or tissue, e.g. a sample of your tumour. This can then be used in research to help with the understanding of the disease.

Biomarker

A biomarker is a biological marker. It is a gene, a molecule or some other biological substance in your blood or cells. It can be measured and used to: - diagnose your tumour, work out how severe a disease is likely to be, the likely response you may have to certain treatments.

Clinical nurse specialist

A specialist nurse who is the main point of contact between you and the rest of your health team. They can offer specialist advice, information and support to you (and your family) about your diagnosis and treatment. They can also refer you to other services, if you need them e.g. fatigue management, seizure management, psychological issues, benefits. NICE guidelines state that all patients with brain tumours "should have a clearly identified key worker" to work with the patients, their relatives and carers, throughout their care. This is likely to be the Clinical Nurse Specialist.

Clinical trial

An experiment that involves patients in a new way of managing a condition. This might include investigating a new treatment, a new way of giving an existing treatment, or a new approach to diagnosing an illness or assessing an outcome after treatment. Trials are vital to establish whether a new approach is safe and effective, and whether it is better than the old approach.

Cognition

“The conscious mental processes that our brain is responsible for, including:

- thinking/reasoning
 - solving problems
 - making decisions
 - understanding social situations ('social cognition')
 - communication
 - perception
 - remembering things”
-

Glioma

A glioma is a tumour that grows from a type of cell in the brain called a glial cell. There are different types of glial cells - the main types being astrocytes, oligodendrocytes and ependymal cells – giving rise to astrocytomas, oligodendrogliomas and ependymomas, respectively. Gliomas are the most common type of brain tumour.

Holistic Needs Assessment (HNA)

A discussion with a healthcare professional involved in your care that will assess your needs as a whole. This will include matters that involve physical, social and emotional needs and can relate to things outside of your illness. You should subsequently be referred to relevant services to help address these needs.

MDT

Multi-Disciplinary Team. A team of healthcare professionals with different specialisations who, once you are diagnosed, work together and oversee your treatment and care.

Rehabilitation

Treatments designed to aid the recovery from illness, injury or disease to as normal a condition as possible.

Treatment plan

The plan and schedule of treatment(s) based on what is considered to be the best treatment option(s) for you. This will depend on many factors, including your tumour type, location and your wishes. Your treatment plan should be a joint decision between you and your health team (MDT).

Watch and wait

A treatment strategy where no immediate treatment is given, but you are closely monitored with regular appointments and scans until symptoms develop or worsen, or your scan changes. This treatment option is often used for low grade, slow growing tumours, where treatment has the risk of causing more harm than doing nothing.

Thanks

We would like to thank the members of our steering group who were instrumental in the development of this guide:

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(Patient)

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(Carer)

Karen Ackling

(Carer)

All the health care professionals who fed back on early draft versions of this guide at our Nurse and AHP Study Day 2016.

And finally all of those personally affected who have shared their stories so we can understand 'how it is' and crucially what changes need to happen.

Notes

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Find us here too

