

**I have been
diagnosed
with a brain
metastasis**
*(a secondary brain
tumour)*

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I have been diagnosed with a brain metastasis (a secondary brain tumour)

What is a brain met?

Brain metastasis occurs when cancer cells spread from their original site in the body to the brain. Any cancer can spread to the brain, but the types most likely to cause brain metastasis are lung, breast, colon, kidney and skin. Brain metastasis may form one tumour or many tumours in the brain.

A tumour that has spread from another cancer site to the brain will be made up of the cancer cells of the original tumour. For example, if you have a brain metastasis from breast cancer, then the tumour in the brain will have the same cells as the cancer in your breast.

Why has this happened?

A diagnosis of brain metastasis (a single tumour) or metastases (more than one tumour) is sometimes referred to as a *secondary cancer* or *brain secondary*. To make it simpler, these tumours tend to be referred to as *brain mets*. This means that you have a tumour or tumours in your brain that appear to have spread from a primary cancer (a cancer that started elsewhere in your body, outside of the brain). The reason why some cancers spread to the brain and the timing of this are not fully understood.

What symptoms might I have?

Symptoms may vary from person to person, depending on the size, location and number of brain mets. These may include headache, nausea, seizures, weakness in one or more limbs, communication difficulties, confusion, unsteadiness or memory problems. Some people may have no symptoms at all.

What treatment can be offered?

Your primary oncology team will ask for your case to be discussed by the **neuro-oncology multidisciplinary team (MDT)**. This is a meeting involving many different health professionals who are experts in brain tumours. They will meet and consider which options are best for you as an individual. Your team will then discuss these options with you before coming to a shared decision. A shared decision is one that is made with you, not one that is made for you.

Surgery – It is sometimes possible to remove surgically a brain metastasis. This is dependent on the size and location of the tumour and how well you are.

Stereotactic radiosurgery (SRS) – SRS is a form of very targeted radiotherapy that aims to control the growth of a tumour and may also shrink it. This is dependent on the size, location and number of tumours and how well you are. SRS may also be referred to as SRT (stereotactic radiotherapy), Gamma Knife or CyberKnife, depending on the machine that is used to deliver the treatment. For more information about SRS, have a look at our **[radiotherapy resource](#)**.

Whole-brain radiotherapy (WBRT) – WBRT involves treating the whole brain with a short course of radiotherapy to control symptoms. This can be useful if you are more unwell or the size or location of the tumour in your brain makes SRS or surgery unsuitable.

Systemic anti-cancer therapy (SACT) – Some anti-cancer drugs are able to cross into the brain from the bloodstream. The drug you are offered is dependent on your primary cancer, and it may be that this is the most beneficial treatment for the brain met.

Surveillance or watchful waiting – In some cases, the MDT may recommend that you do not receive treatment for the brain met straight away. There may be instances where further monitoring is recommended and treatment is offered at a later date.

Steroids – Steroid medications do not treat brain mets but can help with the symptoms caused by their presence in the brain, such as headaches or nausea. They work by controlling any swelling (oedema), which often surrounds brain mets.

You may decide not to opt for any treatment or even not to decide – these are decisions too. Only you know what your context is, what is important to you. You are the expert on you; your clinical team is the expert on treatment options. You should decide together what you want to do.

What are the side effects from the treatment?

Side effects are dependent on the treatments you are offered. You will be provided with information specific to your treatment by your team.

What does this mean for my prognosis?

Once a cancer has spread to another part of the body, it is not possible to ‘cure’ the cancer. However, there are treatments for brain mets that can help to control the growth of the tumours and improve any symptoms that they may cause. Your prognosis will also depend on the treatments available for your primary cancer and any other health conditions that you may have. If you wish, your oncology team can discuss with you what a diagnosis

of a brain met means for your prognosis. Some people find this information useful; others would rather not know. Only you can decide whether you would like an indication of prognosis. Once you have this information, it cannot be taken away. Also, remember that there are always outliers – people who don't fit the average.



How do I know if the treatment has worked?

Your oncology team will monitor your progress with regular brain scans. The purpose of these scans is to check that brain mets are not growing and that no new tumours can be seen.

What happens if more brain mets grow?

It may be possible to offer more treatment. Your primary oncology team will liaise with the neuro-oncology multidisciplinary team (MDT) to consider which options are best for you as an individual. This may include further radiotherapy, as described above, surgery or SACT. Your team will then discuss these options with you before coming to a shared decision with you. Again, you can decide not to opt for further treatment.

I want to live better with brain met

Being diagnosed with brain met can often signal a whirlwind of medical appointments, scans and treatment plans, usually at a time when your life is already in turmoil from a primary cancer diagnosis. You may find yourself thinking, ‘What is next?’

At *brainstrust*, we believe living with a brain tumour, whether it is a primary or a secondary brain tumour, should mean that you can still live your best day every day. In this section, we will talk about what support should be available to you, how you can get it, and some strategies to support you. Your treatment plan and pathway will be individual to you, but the desire to know what support you can have to help with your quality of life is something that many people will experience. See this support as an entitlement.

Remember – You may decide not to opt for any treatment or even not to decide – these are decisions too. Only you know what your context is, what is important to you. You are the expert on you; your clinical team is the expert on treatment options. You should decide together what you want to do.

Side effects

Side effects are dependent on the treatments you are offered and the size, location and number of brain mets being treated. They will vary from person to person, and you will be provided with information specific to your treatment by your team. Side effects may include fatigue, hair loss, headache, nausea, seizure or worsening of any existing problems that the brain met has been causing. These will improve with time, but you may require medications or referral to supportive services to help you manage them. There are also things that you can do to help yourself (self-care).

You may require medications to help with the symptoms of the brain met or the side effects of treatment. Sometimes you may need to continue taking these medications for a long time, and you may need continuing support with this. Your oncology team can refer you to your local community palliative care team, who can help with management of side effects requiring medication, as well as support for emotional well-being. Please note that palliative care is not end-of-life care. Palliative care is also called best supportive care, and it is about enabling you to live your best life.

Steroids are used to control swelling around brain mets. This swelling (sometimes referred to as *oedema*) can cause issues such as headaches, seizures, nausea, speech or mobility problems. Steroids themselves may cause further side effects, such as weight gain, insomnia, mood changes and muscle weakness. You may find it helpful to talk to your oncology team about any side effects you are experiencing from steroids and how to manage these.

Anti-sickness medication (also known as anti-emetics) can help to control any nausea or vomiting caused by the treatment. Sometimes you may need more than one drug to control your symptoms. Some people find that natural remedies for nausea, such as ginger or peppermint, can help too.

Some people may experience headaches. While steroid medications can help with controlling these, sometimes people find they need to take some pain relief at the same time. Your oncology team will be able to advise which pain relief you can safely try alongside your other medications.

Anti-convulsant medication (sometimes called anti-epileptic medication) may be required to reduce the likelihood of a seizure. You may already be taking this, or you may be advised to start when you receive your treatment for the brain met.

Anti-convulsant medications can themselves cause side effects, such as low mood or tiredness. It is very important that you tell your oncology team about any concerns you or your caregivers have regarding any changes in your mood.

You and your caregivers can access more information about epilepsy and how to cope with seizures at brainstrust.org.uk/epilepsy.

Most people feel tired after treatment for brain mets. The level of tiredness varies from person to person. You may find it helpful to read **My Fatigue Book** for practical tips and self-care advice. Your oncology team can refer you to supportive services, such as occupational therapy (OT) and physiotherapy, for help with mobility problems and safety in the home.

Not all treatments for brain mets will result in hair loss. However, practical and emotional support is available to help you. To find out what support is available in your local area, contact your oncology team.

Some side effects from treatment may last a long time, or their onset may be delayed, happening some months after you have finished your treatment. These can be referred to as *late effects*. Your oncology team will discuss with you which late effects may be a possibility after your treatment and how they can be managed.

Scanxiety

When you are diagnosed with a brain met, MRI scans become an integral part of your care plan. Because of this, scanxiety – fear and nerves around both the scan and the results – is something that many people with a brain met diagnosis experience.

1 Bauml, J., Troxel, A., Epperson, C., Cohen, R., Schmitz, K., Stricker, C., Shulman, L., Bradbury, A., Mao, J. and Langer, C., 2016. Scan-associated distress in lung cancer: Quantifying the impact of “scanxiety”. *Lung Cancer*, 100, pp.110–113.

Scanxiety is a known phenomenon (**there is one study in lung cancer patients**¹) describing the fear and worry associated with scanning, both before and after a scan and before the results are given. In an ideal world, we wouldn't have to wait between the scan and being given the results. But the reality is that scans often aren't read on the day of the scan, let alone reported on. There is a significant shortage of neuroradiologists, so sometimes the delay can be a few weeks.

During this time, your quality of life is negatively impacted. It makes no difference where on the trajectory you are. In the early stages, the underlying fear is about cancer growing and the dreaded implications. And in patients who have more aggressive tumours, the fear is based on scans potentially showing a lack of treatment effectiveness or the disease progressing.



Coping with scanxiety

This Know How will go through some strategies to help you cope with scanxiety, so you feel better prepared and more in control in the run-up to MRI scans. It also shares some strategies about how to cope with the wait for results.

Click here to download the **[‘Coping with scanxiety’ Know How](#)**.

You don't need to do this alone

For further support, email *brainstrust* at hello@brainstrust.org.uk, or pick up the phone to us: **01983 292 405**. We run regular **hypnotherapy** sessions that build skills to help you manage scanxiety – [click here](#) to find out about upcoming events.

Exercise and rest following treatment

The brain controls voluntary movement, balance and gait, all essential elements of physical activity. Sometimes the location of a brain met can impact on physical activity and on vision too, which can make mobility more challenging. In addition, therapies can cause fatigue, dizziness, weakness and lack of balance, making the situation worse. And long-term use of steroids can cause muscle-wasting.

This means that exercise may be particularly difficult for some people living with a brain met. Equally, though, exercise may bring the greatest benefits. The most important thing is to do what works for you. For many, walking is easy to build into daily activity. Keep the exercise light, and do what works for you and what motivates you. And if you are having a bad day, even just finding somewhere outside, in nature, to sit and just be can be soul food.

If you have a disability that limits your movement, try some of [these exercises](#) curated by Dom Thorpe, founder of Disability Training.

If balance is a problem, exercises can be done while sitting down. You could practise standing while lightly holding on to a kitchen worktop or heavy piece of furniture. Let go of it intermittently, but stay close enough so you can grab it again if you need it. Exercise in short sessions for three to five minutes a few times a day, rather

than longer single sessions. Add gentle stretching exercises to your regimen. Yoga is great for building strength and for relaxation.

Don't underestimate the benefits of going for a walk. The payback is huge, but pace yourself. If you haven't been for a walk for a while, set a realistic goal of five minutes, gradually increasing the time until you are walking for thirty minutes. And be aware that wherever you end up, you have to leave some spare capacity to get back. If you can't take someone with you, make sure that you always let someone know where you are going. Take your phone if you have one. Walking will help you to:

- maintain a healthy weight
- increase your energy levels
- prevent or manage various conditions, including heart disease, high blood pressure and type 2 diabetes
- strengthen your bones and muscles
- improve your mood
- improve your balance and coordination.²

Rest

The antithesis of exercise. What does rest look like for you? It means different things for different people and is never a case of one size fits all. Rest is important. It stops you getting to the point of exhaustion so that you have to stop what you are doing, regardless of what you are doing. Planning for rest is a critical part of managing your condition. By planning your activities, you can plan to rest too. Only you know what type of rest break works for you, for how long and when. It could be:

2 Ruden, E. et al. (2011). Exercise behavior, functional capacity, and survival in adults with malignant recurrent glioma. *Journal of Clinical Oncology*, 29(21), pp. 2918–2923.

- a few short rests or power naps
- one longer rest at the same time each day
- resting between activities.

Try not to nap after 3 p.m., and only nap for up to twenty minutes. The quality of rest is key. Try to make your rest as complete as possible. This means aiming to switch off your mind and body and, more importantly, asking those around you to understand how valuable this time is for you. You need to be quiet and undisturbed.

Diet

Certain diets and nutritional approaches are often spoken about in the media and elsewhere as being potentially helpful for people living with a brain met diagnosis, which may have caused you to wonder whether you should be thinking about particular nutritional approaches for your health. If you were diagnosed with a primary cancer prior to being diagnosed with a brain met, then the chances are that you have already considered your diet.

There is no evidence to show that any specific food or diet is associated with the development, management or treatment of either a primary brain tumour or a brain met. However, the diagnosis of a brain tumour, whether it is a primary brain tumour or a brain met, can change your relationship with nutrition, food and eating. This can be to do with a desire to eat more healthily, not being able to swallow well, or loss of appetite and the loss of ability to eat regular meals. We suggest focusing on the social aspect of eating – in other words, don't choose a diet that is so exclusive that only you know how to prepare it, or one that prevents you from going out to eat. Focus on eating food, not nutrients. So try eating a balanced, colourful diet. By eating sensibly and well, you can gain a range of antioxidants and fibre, which your body needs.

brainstrust's workshops and resources

We are a treasure trove! However, we also know that just being given links to look at can be overwhelming. We suggest you speak to one of our super support specialists about what it is you are struggling with, either by phone on **01983 292 405** or email at hello@brainstrust.org.uk. We can then share with you the best resources that match your context and your needs. Each of our support specialists is a qualified coach, so they will be able to help you to identify what it is you need.

To see the range of webinars that we run, have a look [here](#). And to find out about the range of support resources we have online, explore [our website](#). Most of our resources are **downloadable**, but we are always happy to pop hard copies in the post to you.

If you find you have any further questions about what is discussed in this resource, don't hesitate to call us on **01983 292 405** or email your support specialist or hello@brainstrust.org.uk. We are here to help you thrive.

The screenshot shows the brainstrust.org.uk website. At the top, there are navigation links: "About brainstrust", "Have I got a brain tumour?", "I have a brain tumour", "Someone I know has a brain tumour", "I am a healthcare professional", "I want to help", "Home", and "Donate". Below the navigation is a header image of a woman and a child. The main content area is divided into several sections:

- Downloads and resources:** A section with a sub-heading "The brain box" and a description: "The brainstrust brain box is a must have support tool for people with a new brain tumour diagnosis and their carers. Fully customizable, with resources relevant to your unique situation. The brain box also comes with brain-like technology and self-care items to remind you to take time to look after yourself!"
- Feel confident, not confused:** A section with a sub-heading "The brainstrust support catalogue" and a description: "The brainstrust support catalogue takes you through the various ways brainstrust can support you. It's a great starting point to find out more about what we do and how we can help you."
- The brain tumour patient guide:** A section with a sub-heading "Know how for practical advice" and a description: "Having access to practical information is key to knowing what support is available. These guides have been specially written with practical information and further reading to help you make your options."
- Who's who in your clinical team:** A section with a sub-heading "My radiotherapy book" and a description: "A companion to a personal treatment option for you, or you have recently had radiotherapy, this resource will help you understand the treatment and how it works in context."
- Proton beam therapy (PBT) guides:** A section with a sub-heading "Proton beam therapy (PBT) guides" and a description: "These guides offer independent, factual information on PBT and what it offers, helping you put proton beam therapy in context with regard to other treatments."

On the right side of the page, there is a sign-up form for a mailing list. The form includes fields for "Last Name", "Email", and "I am", followed by a dropdown menu for "I am a brain tumour patient". Below the form is a checkbox for "I consent to brainstrust processing my personal data" and a "Sign up" button. There is also a section titled "Coaching with brainstrust" with a description: "Coaching with one of our support specialists can help you understand what's important to you, the brain and all questions, embarking with you to create a plan to reach specific goals." and a "Sign up to coaching" button. At the bottom right, there is a "Donate now" button and a testimonial: "If it wasn't for brainstrust supporting me through my experience, I don't know where I would be right now."

I am a caregiver of someone living with a brain met

Being a caregiver is not a role for which we apply, and often it is not one for which we have had any training. The chances are that by now you are an experienced caregiver, as you have supported your loved one through their first diagnosis. At *brainstrust*, we believe that people living with a brain tumour are people first, patients second. And that also means you are a husband, wife, partner, brother, daughter, etc. first, and a caregiver second. You are just as important as your loved one, and by being supported, you will feel more involved, resourced, connected and confident.



As a caregiver for someone who is living with a brain met, you will need to feel comfortable with uncertainty, know who to ask, where to go for help, and be constructive in your inner dialogue with yourself, often when things are really tough. You will need to know where your sanctuary is, and you should use it often. It doesn't need to be anything exotic – it might be an hour with a good book, a walk in the sunshine or a coffee with a friend. We can help you with feeling connected, more on top of things and less alone. Visit [our website](#) to discover how we can help.

I want to hear from others living with a brain met

We can help you move from being lonely to being part of a community. Whether you are a patient or a caregiver, you don't have to face this part of your journey alone.

At *brainstrust*, we don't underestimate the value of talking to someone who has had a similar experience. Our community overwhelmingly reports that a brain met diagnosis is frightening, isolating and bewildering. We have a range of approaches that can help you feel less alone.

Peer support

Talking to someone who has already been through the same experience can help to reduce the isolation, make sense of what is happening and reduce the fear of the unknown.

Our peer support service directly connects you with a peer supporter to help you feel better understood and supported. Peer supporters are trained volunteers who have been through a similar experience to yours, whether you are the patient or caregiver.

Support groups

Our support groups are run online, usually via Zoom. They create online space for the community, where you can meet others in a similar situation. While we facilitate these groups, we know that this is not our space; it is yours to talk about the things that matter to you. We sometimes organise expert speakers to come along to share information – for example, about treatment options or complementary therapies – but we never set an agenda.

Patient stories

Through hearing other people's narratives, you know that you are not the first person to have suffered in this way, although it can feel like it. The pain isolates you, and it simply feels private. It can't be shared. No amount of counselling, support or reading can take away the feeling of desolation when you are diagnosed with a brain tumour – any brain tumour. But we know that hearing about other people's experiences of brain cancer can help you to find your way on your journey. [Here](#) we have created a space for people to share their stories with you. And if you want to add your story, then please get in touch. We live our lives through stories – and yours is an important one to share.

Social media

We currently have a **closed support group** on Facebook. This supportive group is self-regulating, and you will always have a response, no matter what time of day or night you post. Whether it is just a comment that you are feeling down or whether you are seeking an opinion about a side effect or treatment, someone will answer. It is also the easiest way to stay up to date with the latest brain tumour news and support opportunities. If you would like to join the group, then just ask to be added. You can change your preferences or unsubscribe at any time.

Maggie's – everyone's home of cancer care

Just walking into a Maggie's centre feels like you are being wrapped up in a cosy dressing gown. And the cake! There is always a central table loaded with cake. Maggie's centres provide wraparound support for anyone living with cancer, which includes caregivers. You can find out if there is a Maggie's centre near you [here](#).

Macmillan Cancer Support

Macmillan helps everyone with cancer live life as fully as they can. It provides physical, financial and emotional support.

If you find you have any further questions about what is discussed in this resource, don't hesitate to call us on **01983 292 405 or email your support specialist or hello@brainstrust.org.uk. We are here to help you thrive.**

With thanks to:

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To find out more about our work, call **01983 292 405**,
email **hello@brainstrust.org.uk**, visit **www.brainstrust.org.uk**
or follow us on  **twitter.com/brainstrust**
and  **facebook.com/brainstrust**.

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