



ROY CASTLE
LUNG CANCER
FOUNDATION

Understanding brain metastases and lung cancer



Introduction

If you or someone you care for has lung cancer and been told about brain metastases, then it's almost certain you will have a lot of questions.

We have written this comprehensive booklet in partnership with lung cancer experts and people affected by lung cancer so that it is as accurate and relevant as possible. It will help you understand more about your cancer so you can make positive, informed decisions about your care and treatment. Use this booklet along with information provided by your healthcare team.

Remember that most healthcare professionals are only too happy to answer your questions and help you with things that may be unclear or causing you concern.

If you still have questions and want to talk to someone, call our free and confidential **Ask the nurse** service on: **0800 358 7200** or email: **lungcancerhelp@roycastle.org**

You can also contact one of the many support organisations available in our *Living with lung cancer* booklet. Order a copy by calling us on: **0333 323 7200 (option 2)** or look at the contacts on our website: **www.roycastle.org/usefulcontacts**



How treatments and other healthcare services are provided is likely to be affected by the coronavirus (COVID-19) pandemic. Your medical team will make sure you know about any national or local variations to what is described in this booklet. They will work in ways to keep you safe while getting the best possible service.

We would like to acknowledge Ann Husband, who features on the front cover, for her support in helping us to produce this booklet.

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About the brain

The brain is a remarkable and incredibly complex organ and weighs about the same as a large bag of sugar. It controls every single thing you will ever do. It enables you to think, learn, create and feel emotions, as well as controlling every blink, breath and heartbeat.

Most of the brain's activity is beyond our awareness, and we rely on its huge capabilities every moment of every day to keep our systems working. We process food, regulate our temperature and make our lungs work without a thought.

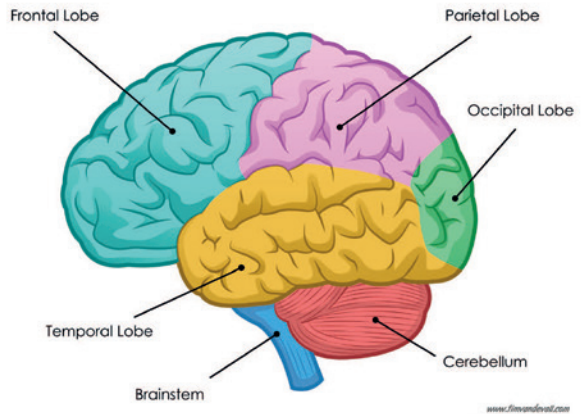
Each part of the brain has different key functions, although some may be shared. The large, folded part of the brain is called the *cerebrum*, and is made up of several areas known as *lobes*:

Frontal lobe – this part of the brain controls our emotional reactions. It also runs our power of reasoning, behaviour, memory and personality.

Parietal lobe – this part controls our sense of touch and how we use our hands.

Occipital lobe – placed right at the back of the brain, this lobe allows us to see.

Temporal lobe – this part processes our hearing, memories and our organisational abilities.



The *cerebellum* sits beneath the cerebrum, and it fine tunes our muscle movements so we can walk and stand, and do things smoothly and accurately.

The *brain stem* is the communications centre through which the brain's decisions get sent to the rest of the body, including control of breathing, blood pressure and heart rate.

When things go wrong, they can show up in changes in how we behave, move or see, or even in how food tastes to us, depending on where in the brain the problem is.

How does cancer start?

The human body is made up of trillions of cells of different types, for example, skin cells, blood cells, bone marrow cells and nerve cells. In babies and children, cells grow and multiply rapidly, forming living tissue and organs.

In adults, this has slowed down, and cells typically divide only to replace dead or dying cells, and to repair injuries. Cancer starts when a cell becomes damaged and begins to grow and multiply without normal controls. These abnormal cells continue to increase in number and typically grow together to form a tumour.

Primary cancer

The tumour at the part of the body where the cancer starts is called a *primary tumour* or *primary cancer*. Cancer can affect any part of the body, including, for example, the liver, the skin, the lungs or the brain. In the case of lung cancer, the primary tumour is in the lung.

As the cancer grows, it can affect surrounding normal tissue by pressing on it, damaging it or even growing into it.

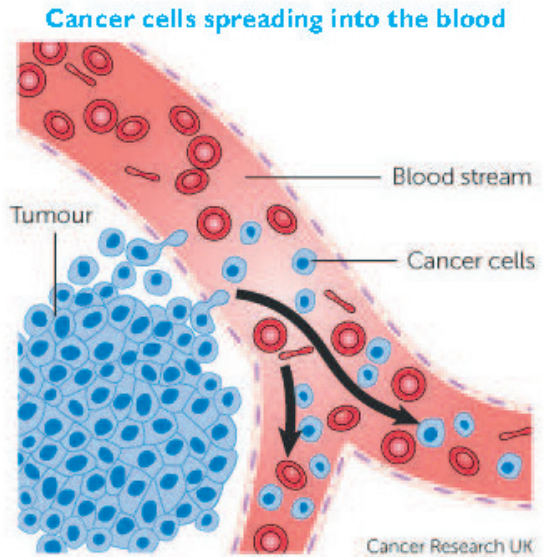
Secondary cancer (metastases)

Sometimes, cancer cells break away from the primary cancer and spread elsewhere in the body, and the cancer can appear in a new location. The cancer cells travel around the body through the bloodstream or the lymphatic system.

When the cancer spreads in this way, the new tumour is called a *metastatic* or *secondary* tumour.

Lung cancer secondary tumours can often appear in the lymph nodes, brain, bones and liver.

These tumours can then begin to grow in the same way as primary tumours and affect surrounding tissue.



When doctors evaluate the extent of a person's cancer, they call it *staging*.

Part of this is the TNM system, where T (followed by a number 1 to 4) refers to the size of the tumour, N (followed by a number 0 to 3) refers to any spread of the cancer to lymph nodes, and M (followed by 0, or 1a, 1b or 1c) refers to any spread of the cancer to other parts of the body.

Combinations of these letters and numbers identify the extent, or spread, of the lung cancer in stages 1 to 4. Stage 1 means the cancer is small and in one area of the lung (*localised*), while Stage 4 means the cancer has spread to another part of the body (*secondary* or *metastatic* cancer).

Secondary cancer affecting the brain

Although any cancer can spread to the brain, some types are more likely to do so than others, including skin, kidney, breast and lung cancers.

Secondary brain cancer is not the same as cancer that starts in the brain (a *primary* brain cancer). Cancers that start in the brain tend to stay in one place. If there is more than one tumour, they are likely to be secondary (*metastatic*) cancer, having spread from another part of the body.

Primary and secondary cancers in the brain are treated differently, so healthcare professionals may need to do different tests to diagnose which one is affecting you.

Brain metastases are relatively common in lung cancer. They occur in around 10% of cases of non-small cell (NSCLC) and up to 50% of cases of small cell lung cancer (SCLC).

How do brain metastases affect people?

Small brain metastases usually have no symptoms, so not everyone will notice any effects, and this may have been the case with you. However, you may have started to show some unusual symptoms and, after being checked out by your doctor, have found out that you have cancer that is affecting your brain.

It may be that you hadn't even thought about cancer before hearing the news, so it is likely to have been a big shock. Doctors may need to do further tests to find out if it is a primary brain tumour, or if it started from somewhere else.

You may already have known about the cancer, and the secondary tumours have been found during investigations, perhaps carried out because you had started showing symptoms, or during or after anti-cancer treatment.

Brain metastases may not currently have any effect on how you feel or what you can do, but they can affect some people in various ways, including:

- headaches
- weakness in parts of the body
- feeling sick
- mood swings and changes in behaviour
- fits or seizures
- problems with co-ordination
- confusion
- lethargy
- problems with reading or talking

Although primary and secondary brain cancers are different, they cause the same types of symptoms. Brain metastases can occur in different parts of the brain and symptoms will vary depending on what the affected part of the brain does.

How doctors assess brain metastases

Once your doctor suspects that cancer has spread to your brain, whether or not you have symptoms, they may carry out different checks and tests to assess the extent and possible impact of the tumours.

Get the true information from your consultant and the team, and don't be afraid to ask the hard questions. The more you know about your cancer, the more you are able to help yourself and your family.

Shaun

These procedures can help your medical team get a clearer picture of what is going on, and gather more information to help you think about what you want to do next:

- **MRI scan (magnetic resonance imaging)**
- **CT scan (computerised tomography)**
- **Neurological examination**
- **Biopsy (tissue sample)**

MRI scan (magnetic resonance imaging)

Magnetic resonance imaging is a type of scan that uses strong magnetic fields and radio waves to create detailed images of the inside of the body.

Carried out by radiographers, MRI scans are the current best way to identify and assess brain metastases. You may also get an injection of a contrast dye called gadolinium to make images clearer during the scan.

An MRI scanner is a short cylinder, open at both ends. You will lie on a motorised bed that is moved inside the scanner. When it's working, the scanner makes loud tapping noises. This is the electric current in the scanner coils being turned on and off. You'll either be given earplugs or some headphones to wear so you can listen to music while the scan takes place. The scan can take up to an hour to complete.



Edinburgh Imaging facility WGH

This procedure is very safe and most people can have it, including pregnant women (though if you are pregnant, you should still let staff know).

Having something metallic in your body doesn't necessarily mean you can't have an MRI scan, but you should make sure you tell the radiographer if you have a metal plate, an artificial joint or a cochlear implant, for example.

If you have a pacemaker, it usually means you will not be able to have a scan of this type.

CT scan (computerised tomography)

A CT scanner uses X-rays and a computer to create detailed, three-dimensional images of the inside of the body. They are carried out by trained operators called radiographers.

The scan itself may last for between 10 and 20 minutes though the whole appointment may last between one and two hours. You will normally be able to go home straight after it and eat, drink and get on with your day.

Brain surveillance

Small brain metastases can remain undetected if they cause no symptoms. Though not standard NHS practice, some oncologists may recommend occasional scans over time so such small tumours may be found early, allowing for early treatment.

On the day of your CT or MRI scan

Some people feel a bit anxious about getting a scan. If you do, let the radiographer know and they may be able to support you to feel calmer, give you a break, or perhaps arrange for you to have a sedative, or support you with deep breathing exercises.

Also, if you wear any jewellery or clothes with metal in them, such as belts and zips, you'd need to take them off before the scan. This could include watches, necklaces, earrings, hearing aids, false teeth and wigs (as some have metals parts). Sometimes you will be asked to undress and put on a hospital gown.

You will also need to tell the hospital if you have any allergies, kidney or blood clotting problems, and if you are taking any medication. This is because radiographers may give you an injection of a dye so that the scanner can get even clearer images.

The staff may also want you to wait for up to an hour after the procedure to make sure you don't react to the dye. If you have had a sedative, you will need someone to collect you afterwards as you won't be allowed to drive.

Neurological examination

An oncologist may do a series of tests to check your nervous system, looking for problems that could be linked to having a brain tumour.

The tests could include checking:

- hand and limb strength, balance and co-ordination
- reflexes, such as your knee-jerk reflex
- hearing, vision and skin sensation
- memory and mental agility (using simple questions or arithmetic)

Biopsy (tissue sample)

A biopsy is where a sample of tumour tissue is taken so that it can be examined under a microscope to identify the cancer type.

If your doctor already knows you have lung cancer, it is unlikely that a biopsy will be needed. Tumours showing on your brain scan will most likely be secondary tumours coming from the lung cancer.

On rare occasions, where the origin of the cancer is uncertain, a biopsy may be done. The biopsy allows your doctors to be absolutely certain what the tumour is and what the best treatment options are for you.

Under general anaesthetic, the surgeon drills a small hole, known as a burr hole, in the skull. A very fine needle is then passed through the hole into the tumour to remove a small sample.

The sample is sent to the hospital's pathologist who examines it closely to identify what type of cancer it is. It may show that the tumour is a primary brain cancer, having developed from brain cells.

However, it may show that the tumour is in fact a secondary cancer that has developed from a primary cancer elsewhere. The tumour may be formed by cancerous cells that have spread (*metastasised*) for example, from the cancer in your lungs.

Knowing what type of cancer it is helps make sure you get the right treatment for the type of cancer found as soon as possible.

While some hospitals may do a biopsy like this as a day case, some may have you stay in hospital for a few days after the procedure. The results may be ready in a few days though it can take a bit longer. Your medical team will tell you when you can expect to hear.

The next steps – deciding what’s best for you

Having brain metastases means that your primary lung cancer has spread from its original location.

If you have been having symptoms or tests, your doctors will likely have spoken to you about the possibility of secondary brain cancer. However, this doesn’t necessarily make it any easier for you, and it can still be a frightening time. You may find it hard to take it in, especially already having had to come to terms with a lung cancer diagnosis.

There are a number of options for helping people with brain metastases. Treatments offered may:

- shrink the tumours
- slow the tumours’ growth
- remove the tumours
- control symptoms

The best options vary from person to person depending on a range of factors. For example, people who have solitary metastases (one tumour) and are generally well, benefit from radiotherapy (see page 18) or surgery (see page 24) with better long-term prospects. For others, treatments may prioritise managing symptoms and maximising quality of life. This may be called *best supportive care* or *palliative care*.

Some people see any treatment option as a chance to have more time with loved ones or to achieve things they have always wanted to do. This is motivation enough to sign up for whatever is on offer, knowing that any active treatment, such as surgery or radiotherapy, is not without risk.

Going ahead with treatment would mean spending time going for treatment and possibly managing side effects. This may or may not work for you. Even if you are offered treatment, you can still choose if you want to go ahead with it or not.

Talk through your choices with your family or others close to you, and the people involved in your care, such as your oncologist, lung cancer nurse or GP. They will do their best to answer your questions and support you in deciding what you want to do next.



“The main thing to remember is that there are treatment options. Talk to your lung cancer nurse if you are worried about any changes in your health as early treatment is always best, and they can help take the worry out of a situation for you.”

Sharon, lung cancer nurse specialist

Treatment for brain metastases

This section will help you think about what you want to do next and tells you a bit about the treatments for brain metastases that may be available to you.

- **If you want to think about treatment**
- **Medicines to reduce symptoms**
- **Radiotherapy**
- **Chemotherapy, targeted therapies and immunotherapy**
- **Surgery**
- **Clinical trials**

It is important to remember that any treatment for brain metastases is primarily about managing symptoms and improving your quality of life. Your doctor may recommend more than one type of treatment.

If you want to think about treatment

There are several treatments available that you could choose at this stage. Although the healthcare professionals can advise which may be best for you, based on their assessment of the type, extent and location of your tumours, only you can weigh up the pros and cons and ultimately decide what you want.

Just because you have treatment options doesn't mean that you have to take them. Find out as much as you can about these from your medical team. A group of healthcare professionals, known as a multidisciplinary team (MDT), will talk about your case to work out the best treatment options for you.

They will take into account the outcomes of any scans and X-rays and other tests you may have had that show the size and location of the cancer, and your general health and medical history. Some of the more likely options and side effects are described on the following pages.

Deciding what you want to do next can be a stressful process, and some of the side effects of any treatment can be hard to deal with. If you feel low or depressed, speak to your doctor or lung cancer nurse. They may refer you to other healthcare professionals who might be able to support you, such as a counsellor. There may also be medication that can help.

Medicines to reduce symptoms

Many symptoms of brain tumours are caused by the pressure and swelling as the tumours grow. Doctors can use drugs known as steroids to reduce swelling quite quickly and improve symptoms.

While most people may feel better with short-term medication, others may need longer treatment, perhaps over several months, to keep symptoms under control.

Most patients start on a steroid called dexamethasone, and symptoms may generally improve within 24 to 72 hours.

As with so many powerful drugs, steroids can also cause side effects, including:

- weight gain and increased appetite
- muscle weakness
- fluid retention (swollen hands, feet and ankles)
- difficulty sleeping
- changes in mood and behaviour
- increased risk of infection
- changes in blood sugar levels

They may be given at the lowest dose possible that still shows benefit to minimise these side effects.

Having fits or seizures is one of the symptoms of having brain metastases, but not everyone will have them. Drugs known as anti-convulsants will help to manage the seizures.

There are several drugs available, and your doctor will choose the one that's right for you. They will also monitor your progress and consider changing your dose, or the medication itself, if it is not working well for you, or you are having unpleasant side effects.

Some of the side effects of taking anti-convulsants include:

- drowsiness
- a lack of energy
- agitation
- headaches
- uncontrollable shaking (tremors)
- rashes

Some anti-convulsants may interact with other treatments you may be getting, so if you notice any changes in your health, speak to your doctor.



Radiotherapy

Radiotherapy is a treatment that uses high energy X-rays to kill cancer cells, and is the most common treatment for secondary brain tumours. It can be used as the main treatment for tumours that are hard to reach, or after surgery to try to destroy small amounts of tumour that remain (known as *adjuvant radiotherapy*).

Your radiotherapy treatment will be given by a machine called a linear accelerator, or *Linac*. The amount of radiotherapy used in your treatment will depend on the number of metastatic tumours and where they are. It is a painless procedure and usually given in a series of short, daily treatments for a week or two.

Cancerous tumours don't shrink immediately after radiotherapy treatment. It can take several days or weeks for this to happen and for you to notice the beneficial effects.

Stereotactic radiosurgery (SRS)

Although this treatment has the word surgery in its name, it is not an operation. It is actually a radiotherapy treatment given in one large dose. You may also hear people talk about Gamma Knife or Cyberknife, for example, referring to the type of machines that may be used to deliver the treatment. It may also be called *stereotactic radiotherapy*.

SRS is a specialised treatment that precisely focuses radiotherapy treatment on the tumour, with the intention of sparing surrounding healthy brain tissue from significant damage.

Because the focus of the beams needs to be accurate, you will get a made-to-measure face mask to keep your head absolutely still during the procedure. The mask is not painful and you will still be able to see and swallow when it is in position.

You will then have a CT and/or MRI scan, with the mask in place. This gives precise and up-to-the-minute images of the tumour to be treated, and accurately shows where it is in relation to the mask.

SRS is available in specialised centres across the UK and is not suitable for every patient. Whether or not you are considered for this treatment will depend on the characteristics of your cancer. Your cancer doctor will be able to tell you more.

Whole brain radiotherapy (WBRT)

For some people, whole brain radiotherapy (WBRT) may be an option. This can treat multiple tumours as well as small, undetectable tumours that may be developing in different areas of the brain.

The advantages of WBRT are that it can treat small, large and multiple tumours at the same time, and tumours deep in the brain that are unreachable with surgery.

The benefits of this type of radiotherapy depends on a number of factors¹. It is important, therefore, to talk this through with your doctor and ask about the side effects, outcomes and quality of life any treatment may give.

Radiotherapy works by permanently damaging the DNA of cancer cells. DNA (deoxyribonucleic acid) makes up the genetic code that tells cells what to do. If it is damaged or destroyed in the cancer cells, they should stop dividing and the tumour can stop growing or even shrink.

Normal tissue around the targeted tumour may also get affected, but the cells in normal tissue are usually able to repair the DNA damage and continue to grow normally.

¹ See the [QUARTZ trial – The Lancet 2016; 388: 2004-14 20](#)

After radiotherapy, temporary damage to normal tissue around the treatment area can cause some side effects, though the risk is low and the side effects are likely to be short lived. Side effects from SRS are similar to those with WBRT though they are likely to be milder.

Some people may feel sick or be sick and this should be easily treated with anti-sickness medication or steroids. Radiotherapy may also cause you to feel tired or sleepy around two to four weeks after treatment.

Most people who have WBRT lose their hair but it grows back. With SRS, hair loss will likely be limited to treatment sites. Occasionally, the scalp may become red or sore. This tends to get better after a few days or weeks.

People are often concerned that radiotherapy to the brain will affect their memory and overall cognitive function. However, while there is a small risk of slight decline in memory some months after treatment, the risk from treatment is slight and people tend to return to their normal activities. In any case, the risk of damage from treatment is likely to be less than from untreated brain metastases.

If you have symptoms and they don't ease up, or you are worried about how you are feeling after treatment, speak to your cancer doctor or lung cancer nurse.



Please see our *Radiotherapy for lung cancer* booklet for more information. Order a copy by calling us on **0333 323 7200** (option 2).

Chemotherapy, targeted therapies and immunotherapy

If you were told about brain metastases at the same time as being told about your lung cancer, this may also be the first time anyone has spoken to you about chemotherapy or targeted therapies. Chemotherapy uses special drugs that kill tumour cells and are given by tablet or injection. They then flow through the bloodstream to the tumour and take effect.

Historically, however, this sort of systemic treatment has had limited value in treating brain metastases. This is because the brain is protected by what is known as the blood brain barrier. This is a protective, tight seal formed by the cells of the brain's blood vessels. Its purpose is to keep many harmful substances, transported in blood, away from the brain.

Choosing whether to have chemotherapy for brain metastases can be a difficult decision. The potential risks and benefits depend both on the cancer type and how well you are. It's important to have an open discussion with your oncologist about this decision.

Dr Seamus Grundy,
Consultant Respiratory Physician,
Salford Royal Hospital

While cancer cells are able to pass into the brain, this barrier blocks most chemotherapy drugs. This means it can be a safe haven for tumour cells, allowing them to settle and begin to multiply. Some cancer cells may also develop drug resistance. Sometimes the location of the tumour itself may disrupt the barrier.

As systemic and other treatments for lung cancer improve, people are living longer. Coupled with more accurate diagnosis through CT/MRI scans, brain metastases are becoming more common. Some treatments, particularly some of the newer types of drugs mentioned below, are now being found to have a positive effect on brain metastases.

For people with small cell lung cancer (SCLC), brain metastases identified at the same time as diagnosis have been found to respond to chemotherapy at a similar rate to tumours elsewhere in their body.

If you have non-small cell lung cancer (NSCLC) and have not previously had chemotherapy, brain metastases may respond to it to the same extent as the cancer elsewhere in your body does. If you have previously had chemotherapy to treat your lung cancer, then it is less likely to work on the brain metastases.

However, there are other drugs used to treat some NSCLC patients whose cancer cells show a particular type of change or mutation, when tested. The treatments are known as targeted therapies and work by stopping cancer cells with these mutations from multiplying.

In only about 10% of NSCLC cases, these tests may find changes in the EGFR (epidermal growth factor receptor) gene. For these people, treatments using EGFR inhibitors such as afatinib, dacomitinib, erlotinib, gefitinib and osimertinib (brand names Giotrif[®], Vizimpro[®], Tarceva[®], Iressa[®] and Tagrisso[®]), show effectiveness in treating brain metastases where enough of the drug is able to cross the blood brain barrier.

A lower percentage of patients (2-7%) test positive for the ALK (anaplastic lymphoma kinase) gene, and these cancer cells show some sensitivity to ALK inhibitor targeted therapy drugs. Currently approved drugs alectinib, brigatinib, ceritinib, crizotinib and lorlatinib (brand names Alecensa[®], Alunbrig[®], Zykadia[®], Xalkori[®] and Lorviqua[®]) are shown to be effective in treating brain metastases.

Other targeted therapy drugs are currently being developed and may have a role in future treatments.

The side effects of chemotherapy and targeted therapies can be similar, though specific drugs can cause more of some symptoms than others.

Some people may receive immunotherapy. This is an anti-cancer treatment that works by encouraging your immune system to work against cancer cells and shrink tumours. This type of treatment has been shown to be effective for patients with lung cancer that has spread to the brain.

Immunotherapy can cause different side effects to chemotherapy and targeted therapies. Your cancer team will speak to you about these if immunotherapy is a treatment option for you.

If you have already had such systemic treatments, you may be familiar with the side effects and have found ways to manage them.

Your medical team will talk to you about your particular treatment and what you can expect. The patient information leaflets that come with each drug will tell you which specific side effects the drug may cause.

If you develop a high temperature (over 37.5°), dizziness, difficulty breathing or a fast heart rate, this could mean you are becoming quite unwell and you would need to contact your cancer doctor or lung cancer nurse specialist, or call NHS Direct or NHS 24 on 111, to check if you need urgent medical help.



Please see our *Chemotherapy for lung cancer*, *Targeted therapies for lung cancer* and *Immunotherapy for lung cancer* booklets for more information about side effects. Order a copy by calling us on **0333 323 7200** (option 2).

Surgery

This may be a good option for treating brain metastases if there is only one tumour, or a particular tumour causing significant symptoms, that can be easily reached. The factors your doctors will take into account will include the size, location and type of tumour, your overall health and your medical history.

Surgery can also reduce swelling and pressure in the brain. This can also ease some other symptoms, and perhaps reduce the amount of medication you may need to take.

The operation is known as a *craniotomy*, and it is carried out under a general anaesthetic. A section of skull would be cut out to enable the neurosurgeon to reach the tumour. After removing as much of the tumour as possible, the piece of bone is fixed back in place.

After the operation, it's not uncommon to initially feel worse than you did before it. Surgery may cause some swelling in and around the brain, though this can be more limited if you are already on steroids. Symptoms may include dizziness, confusion, speech problems and weakness.

While these symptoms may come and go, they will usually reduce over a few days or weeks. The symptoms you may experience will vary depending on the location of the tumour. Also, because the surgery itself may damage tissue around the tumour, some of the side effects may be permanent.

Other services that may support you include physiotherapy, occupational therapy, and speech and language therapy (see page 28). Your doctor or lung cancer nurse may refer you to them.

Clinical trials

Clinical trials are an essential part of medical research. They can find out if new treatments are better than current best practice.

On some clinical trials, your condition may be monitored more regularly than with standard care. This may include more blood tests, CT scans or other cancer tests. You may also spend more time with your doctor or nurse.

This could mean that any changes in your health, whether or not they are related to the treatment you are having, are frequently picked up and acted upon earlier than if you were not in a trial.

It is important to keep in mind that the drug trial or research study on a new treatment is only carried out to find if the new option is better than what is currently offered. It may be the same, or it may be worse. Drugs tested in trials may also not be made available to everyone on the NHS after the trial ends.

Ask your cancer doctor about any clinical trials. Getting into a trial is often based on being able to meet some very specific criteria. Your cancer doctor will be able to tell you if you are eligible.

To check what clinical trials are available, visit:



UK Clinical Trials Gateway

www.bepartofresearch.nihr.ac.uk

Cancer Research UK

[www.cancerresearchuk.org/about-cancer/
find-a-clinical-trial](http://www.cancerresearchuk.org/about-cancer/find-a-clinical-trial)

What other support can I get?

Palliative care

Palliative care describes care and support that is given to someone when a cure is not possible. It may last days, weeks or even longer.

Many healthcare professionals, both in hospitals and in the community, including GPs and nurses, provide palliative care as part of their jobs. This care is about making you as comfortable as possible, by managing your pain and other distressing symptoms. It also involves psychological, social and spiritual support for you and your family or carers.



Ask your cancer doctor, lung cancer nurse or GP about palliative care.

Using hospice services

Every year hospices provide care and support to around 360,000 people, including adults and children with life-limiting or terminal conditions, and their families and friends.

We believe that everyone matters throughout their life right up until they die, and that no one should die in avoidable pain or suffering.

Hospice UK

There are hospices in many areas of the UK. They offer a range of personalised care provided by professional staff and volunteers. As well as taking care of people's physical needs, they also look after their emotional, spiritual and social needs. They also support carers, family members and close friends, both during a person's illness and during bereavement.

Hospice care is free for everyone, and is provided for however long it is needed, which could be days, weeks or even months.

Hospices provide a range of services, including:

- pain and symptom control
- psychological and social support
- rehabilitation
- complementary therapies, such as massage and aromatherapy
- counselling
- spiritual care
- practical and financial advice
- support in bereavement



You can find out more about hospices, including finding your nearest one, at: www.hospiceuk.org

Other support services

Some of the problems and symptoms associated with brain metastases don't get resolved when the tumour is removed or treated. For example, you may continue to have muscle weakness, fits or seizures, problems walking, or difficulties with speaking or swallowing.

There are services available that can give you extra support to help you overcome or adapt to some of these problems:

- Physiotherapy – this can help you maintain or improve your strength, mobility, balance and co-ordination through exercise and other advice. Physiotherapy can also help you with breath control, as well as coughing and chest clearing techniques.
- Occupational therapy – if you are struggling with some every day activities, like getting up stairs, bathing or cooking, an occupational therapist will look at equipment or alterations that can be made to help. They can also help you deal with fatigue or poor sleep, as well as some aspects of going back to work, if this an option for you.
- Speech and language therapy (SALT) – this is a specialist team that helps people who find speaking clearly or loudly enough difficult, or who are not able to eat and swallow properly.

If you are finding it hard to get around, do things about the house or people are finding it hard to understand you, speak to your lung cancer nurse or consultant. They will refer you to the services you need.



What if I want to drive?

Driving is a complex activity, where steady mental and physical capacity is essential. Brain metastases are unpredictable in terms of the effects they can have on a person's capacities and they can cause sudden disabling events, such as seizures.

Because of this, any driver diagnosed with brain metastases must STOP driving to minimise any risks to themselves or others. Otherwise, they run the risk of a hefty fine, have invalid insurance and face prosecution if they are involved in an accident. Many people who hear this news tell us that it has been a very difficult thing to come to terms with as it can significantly change their independence and what they can do.

I have a wonderful network of family and friends and they make sure I get out and about and take me to all my hospital appointments.

Ann

There is a legal responsibility for driving licence holders to tell the Driver and Vehicle Licensing Agency (DVLA), or the Driver and Vehicle Agency (DVA) in Northern Ireland, about certain medical conditions that could affect their driving. The agencies would then assess the individual case and make recommendations or restrictions.

However, in the case of brain metastases, itself a notifiable condition, the outcome will certainly be a driving ban. Some people just decide to stop driving for good, without notifying the agencies, and that is enough.

If you do notify the agencies (see page 30), they will tell you about what happens next, and if further medical enquiries are needed. They will also let you know if and when you may be able to reapply for your licence.

In some situations, however, a lorry, coach or bus driving licence may be permanently revoked from the outset.

Reapplying for your car or motorcycle licence could be after one year, usually two, and only if you are clear of brain metastases and your cancer is controlled, or if you are receiving immunotherapy or a targeted therapy and your brain metastases are stable or improving.

This is a sensitive subject, and we can only give you some guidance about the process. Always check with the DVLA or DVA, and your GP or consultant, about your own situation.

Both agencies will write to you about what happens next. They may ask for permission to make further medical enquiries, ask you to surrender your licence, if you haven't already done so, or revoke your licence, and give a medical reason why. They will also tell you if and when you may reapply for your licence.

DVLA

Car drivers and motorcyclists can notify the DVLA using Form BI, available online. If you have a lorry, bus or coach licence, use Form BIV. Fill in the form and send it to them.

Web: www.gov.uk/brain-tumour-and-driving

Post: Drivers Medical Group, DVLA, Swansea, SA99 1TU

Fax: 0300 083 0083

DVA

Send both parts of your driving licence with a covering letter detailing your condition to them, or contact them by telephone or email, and they will send you a medical questionnaire.

Web: www.nidirect.gov.uk/articles/how-tell-dva-about-medical-condition

Post: Drivers Medical Section, DVA, Castlerock Road, Waterside, Coleraine, BT51 3TB

Phone: 0300 200 7861

Email: dva@infrastructure-ni.gov.uk

Putting your affairs in order

There is no getting around the fact that, if your lung cancer has spread to your brain, it is serious. It means that your cancer is not curable. For some people, though not all, brain metastases can be managed, reduced or perhaps eliminated, even if temporarily.

Finding out about brain metastases can be a lot to take in and now may be the time to ask some difficult questions and make significant decisions. Facing the prospect of an incurable illness often brings people a new perspective on life and what is important to them.



Coming to terms with dying is not easy. You may have so much you want to do and people you want to see over an uncertain length of time.

Doctors are unlikely to give you anything other than the broadest figures for how long you may be around to get things done. It could be from a matter of weeks or months, though everyone is different, and some people do buck the trend and confound the medics.

Many people also have a lot of questions, some of which may be difficult to answer. 'How will my cancer progress and how will that affect me? What will happen if I can no longer look after myself or get around? When I am unwell enough to die, how will I be cared for?'

Understandably, people can find this incredibly hard. If you are worried about what happens if your health gets worse, it may be worth considering now what you want and who best to involve in planning and understanding what is important to you.

It can be helpful to get some support and consider these things when you feel able. It may be that you are ready to talk about some things before others feel able, such as your family or those who are caring for you.

You might want to use your health team, a helpline or an online forum as a way of preparing and rehearsing what you want to say and the things you need to sort.

One aspect of this may be considering how your treatment progresses and who makes decisions if you can no longer do so without help. This can involve setting out what is sometimes known as a “*living will*” or sorting out a legal power of attorney (LPA), where you can nominate the person you want to make decisions on your behalf and what decisions they can make. There are two types of LPA. One relates to your financial affairs, the other relates to your health and social care.

It may be worth thinking about places where you would like to be cared for, perhaps in hospital, at home or in a hospice. Services are available to support the choices you might want to make around how you are looked after at different stages if your health changes. Many hospices also offer services to people living with long-term health problems and can offer respite and home-based support, as well as end-of-life care.

If you are caring for someone whose health is affected, it may be an emotional and upsetting time. It can be useful to talk and plan together, and to have the conversations that may be challenging, but it will help all of you when things are difficult.



The lung cancer team and palliative care team are there to support all those affected, and getting help to think through what you need to support you in your caring role can reduce some of your fears and worries.

Useful contacts

Roy Castle Lung Cancer Foundation: 0800 358 7200

Macmillan: 0808 808 00 00

Hospice services: www.hospiceuk.org

National Bereavement Service: 0800 024 6121

Citizens Advice Bureau: www.citizensadvice.org.uk

Legal advice: www.lawsociety.org.uk/for-the-public/common-legal-issues/making-a-will

Finances

One of the practical things that you may want to talk about with those who are caring for you is your money affairs. Advice is available from your cancer team on additional benefits that may be available to you if you have a life-limiting illness.

Your local authority may also have welfare rights officers who help make people get all their benefit entitlement. Some are able to make home visits.

You may also ask your GP to fill in a DSI500 form. This is from the Department for Work and Pensions and will make sure any benefits claims are dealt with quickly. You may also qualify for a Blue Badge to help with parking.

Your income, perhaps from your salary or pension, might be affected by your changing health, and you may need to work out a new household budget. Some people may choose to cash in or draw down a lump sum from a private pension. If you have a mortgage protection policy, or insurance that covers long-term illness, it may be worth checking what cover this can provide.

If you are struggling financially, Roy Castle Lung Cancer Foundation offers one-off grants of up to £150. You can find out more and apply here:

www.roycastle.org/help-and-support/patient-grants

Macmillan and the Citizens Advice Bureau can provide good independent sources of advice. Macmillan also offer small one-off grants to people with lung cancer with limited savings and low income.

While it might not be easy to think about, it can give peace of mind to make sure you have an up-to-date will. It can be a task that gets put off and you may not know where to start. Writing a will needn't be expensive or complicated.

About our lung cancer information

We follow established quality standards and production principles to make our information trustworthy and easy to read. It is evidence based, following national clinical guidelines and best practice for managing lung cancer.

We believe information that is clear, accurate, evidence based, up to date and easy to use allows people to become better informed and more involved in their health and care.

Our information is written either by our information team or by lung cancer experts. We have a panel of lung cancer experts made up of doctors, nurse specialists and other health professionals involved in the treatment and care of people affected by lung cancer. These people help us on a voluntary basis. You can find out about our Expert Panel at www.roycastle.org/expertpanel

This booklet has been published in partnership with Lung Cancer Nursing UK.



Our information is also reviewed by members of our Reader Panel (made up of people who have experience of lung cancer). This makes sure our lung cancer information meets their needs. You can find out about our Reader Panel at www.roycastle.org/readerpanel

You can find references to sources of information within this booklet at www.roycastle.org/evidence

If you have suggestions for new publications or additions or improvements to our existing range of booklets and factsheets, please let us know at info@roycastle.org

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ROY CASTLE
LUNG CANCER
FOUNDATION

Roy Castle Lung Cancer Foundation is the charity that gives help and hope to people affected by lung cancer. The charity has two aims – supporting people living with lung cancer and saving lives.

Supporting people living with lung cancer

Working closely with lung cancer nurses, we provide information, run lung cancer support groups and offer telephone and online support. Our patient grants offer some financial help to people affected by lung cancer.

Saving lives

We fund lung cancer research, campaign for better treatment and care for people who have lung cancer, and raise awareness of the importance of early diagnosis. Our lung cancer prevention work helps people to quit smoking and encourages young people not to start smoking.

Contact us

For more information, call our Lung Cancer Information and Support Services:
0333 323 7200 (**option 2**)
or visit our website: www.roycastle.org

Head Office

Cotton Exchange Building,
Old Hall Street,
Liverpool, L3 9LQ
Email: foundation@roycastle.org

Information and Support Services

98 Holm Street,
Glasgow, G2 6SY
Email: info@roycastle.org

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