

Spinal tumours



Brain & Spine
Foundation

The Brain & Spine Foundation provides support and information on all aspects of neurological conditions. Our publications are designed as guides for people affected by brain and spine conditions – patients, their families and carers. We aim to reduce uncertainty and anxiety by providing clear, concise, accurate and helpful information, and by answering the common questions that people ask. Any medical information is evidence based and accounts for current best practice guidelines and standards of care.

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Introduction

This booklet provides information on spinal tumours in adults. The booklet describes spinal tumours and provides information on common symptoms, tests and investigations, and possible treatments. It also provides information on recovery and returning to everyday activities. Sources of further support and information are listed in the **Useful contacts** section. References are available on request.

About the spine

The spine is made up of the spinal cord and the backbone.

The spinal cord is a bundle of nerves that extends from the brain to the lumbar section of the spine (lower back). Different sections of the spinal cord are responsible for different movements and functions of the body.

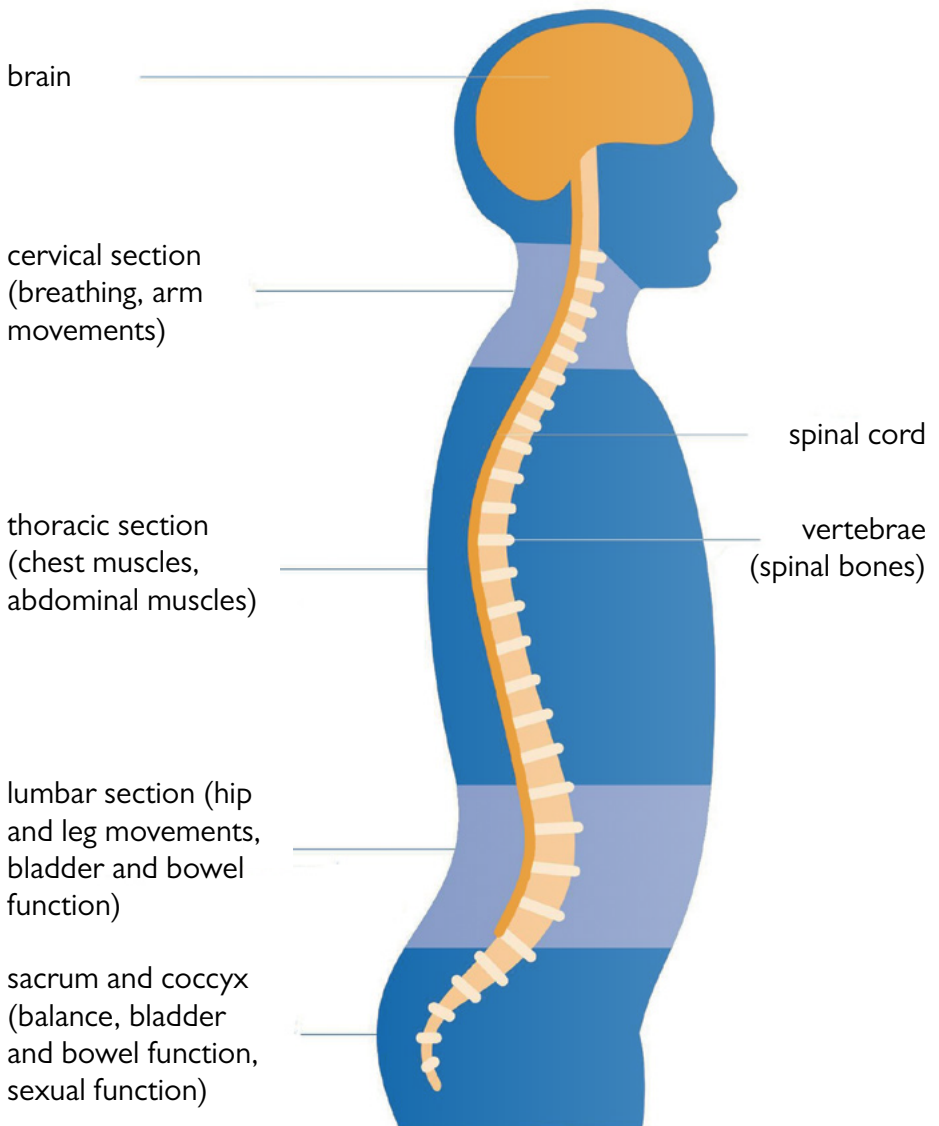
The spinal cord is surrounded by spinal bones called vertebrae. These individual bones make up the backbone. The spinal cord extends from the brain to the lumbar section of the spine. The backbone continues beyond the lumbar section to the coccyx (tail bone). Some of the muscles in the back also form part of the structure of the spine.

The brain and the spinal cord are surrounded and protected by cerebrospinal fluid (CSF). This fluid is contained by the dura (or dura mater) which is the outermost membrane (layer or 'skin') that covers the brain and spinal cord.

The brain and spinal cord are part of the central nervous system. Nerves that branch out from the spinal cord through the dura and vertebrae become part of the peripheral nervous system.

The **central nervous system** is made up of the brain and spinal cord. The **peripheral nervous system** is the network of nerves that connects the central nervous system to the rest of the body. Messages (nerve impulses) that control the body's actions and functions travel from the brain along the spinal cord. The peripheral nerves then carry these messages all over the rest of the body.

Diagram of the spine and the main functions of each section



Common questions

What is a tumour?

Our bodies are made from building blocks called cells, each with its own structure and function. Cells grow and multiply naturally and normally as you grow and when your body repairs tissue damage (for example, when your skin heals after a cut or graze).

A tumour is a swelling or lump that forms when certain cells grow and multiply abnormally.

What is a spinal tumour?

A spinal tumour is an abnormal growth of cells in the spine.

If cells in the spine grow and multiply abnormally to cause a spinal tumour, this is called a primary tumour.

If abnormal cells have spread to the spine from a tumour in another part of the body, this is called a secondary tumour or a metastasis ('secondaries' or metastases when talking about more than one).

What are the different types of spinal tumours and where do they occur?

Primary tumours are graded by doctors according to the speed at which they are growing. Slower-growing tumours are given lower grades (grades 1 and 2) and faster-growing tumours are given higher grades (grades 3 and 4).

The grading system was devised by the World Health Organisation.

Depending on the grade, doctors will refer to a tumour as being 'non-malignant' or 'malignant'. The grade of a tumour will also help doctors to decide on the most appropriate treatment.

Non-malignant spinal tumours

Low grade spinal tumours can grow but they do not spread and they do not cause secondary tumours to grow in other parts of the body. However, these tumours can grow to a considerable size, causing damage by putting pressure on the tissue around them in the spine.

Historically, the term 'benign' has been used to refer to grade 1 and grade 2 spinal tumours. However, increasingly this term is not being used. This is because, by definition, a 'benign condition' is one that doesn't cause harm whereas in fact all spinal tumours have the potential to cause significant harm, even if they are slow growing and less aggressive when they are discovered. In this publication, we will use the term 'non-malignant' to describe low grade spinal tumours.

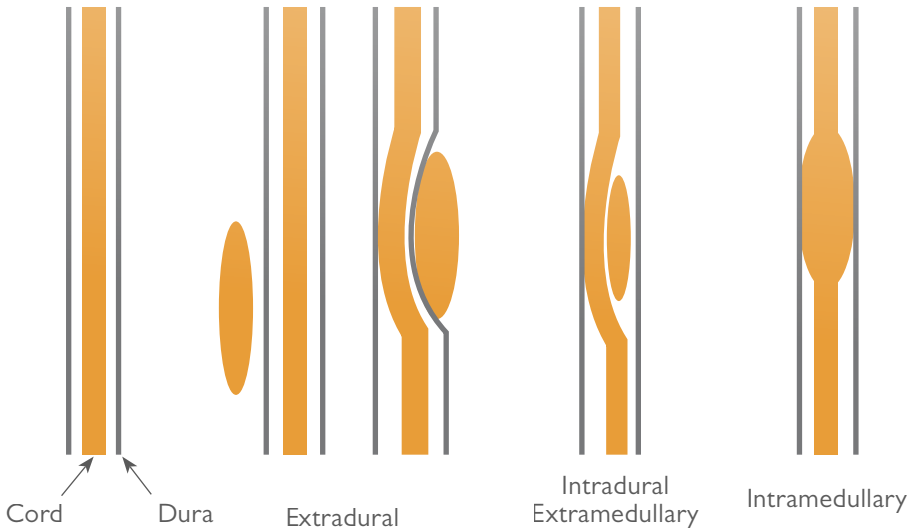
Malignant spinal tumours

High grade spinal tumours are referred to as 'malignant' spinal tumours. Malignant spinal tumours are cancerous. They do spread and destroy the tissue surrounding them. The rate at which they invade the surrounding tissue depends on how malignant they are. They can also cause tumours to grow in other parts of the body, although this is unusual for spinal cord tumours.

Primary spinal tumours can be non-malignant or malignant depending on their grade. Doctors do not grade secondary (metastatic) spinal tumours because, having spread from a malignant tumour elsewhere in the body, they are always malignant.

The most common spinal tumours are malignant metastases that have spread to the spine from malignant primary tumours in other parts of the body.

Malignant primary tumours in the prostate, breasts, lungs, kidneys and bowel are the most common sources of malignant metastases in the spine.



The brain and spinal cord are covered by a protective outer membrane (a layer or a 'skin') called the dura. Tumours that occur outside the dura are called **extradural tumours**. Tumours can also occur inside the dura (non-malignant spinal tumours usually occur inside the dura). Tumours that occur inside the dura but outside of the spinal cord are called **intradural extramedullary tumours**. Less commonly, tumours can grow inside the spinal cord itself. These are called **intramedullary tumours**.

Any section of the spine can be affected by tumours, from the top of the neck down to the coccyx (tail bone).

Secondary (metastatic) tumours in the bone are the most common type of spinal tumour. Primary bone tumours are rare.

Names of spinal tumours

The name given to a tumour is often based upon the type of cell that is growing abnormally or its particular location in the spine. For example, gliomas grow from glial cells and, more specifically, astrocytic gliomas (astrocytomas) grow from particular glial cells called astrocytes ('star-shaped' cells).

Some examples of the names of specific tumours include

- chordomas (tumours in the bone)
- myelomas, neurofibromas and lymphomas (extradural tumours)
- meningiomas, schwannomas, and ependymomas (intradural tumours)
- astrocytomas and ependymomas (intramedullary tumours).

This is not an exhaustive list and there are many other rarer spinal tumours that are not named here. Your consultant will be able to discuss your specific type of tumour with you.

What are the symptoms of a spinal tumour?

The symptoms of a spinal tumour depend on factors such as the size of the tumour, its exact location within the spine and which section of the spine is affected.

People might not experience all of the main symptoms of a spinal tumour but they are likely to experience more than one of them.

Back pain

The most commonly experienced symptom of a spinal tumour is pain in or near the spine. Often the pain is not relieved by resting and it might get worse when you lie down or go to bed. Pain that starts in the back before radiating around the body is a sign that nerves could be affected. This type of radiating pain might be caused by



a tumour but it is not necessarily the case. Pain spreading down an arm or leg from the spine is a common symptom of a slipped disc.

Spinal tumours are rare and it is important to note that aches in the neck or general backache are most likely to be due to wear and tear in the joints or discs or caused by a problem like a slipped disc.

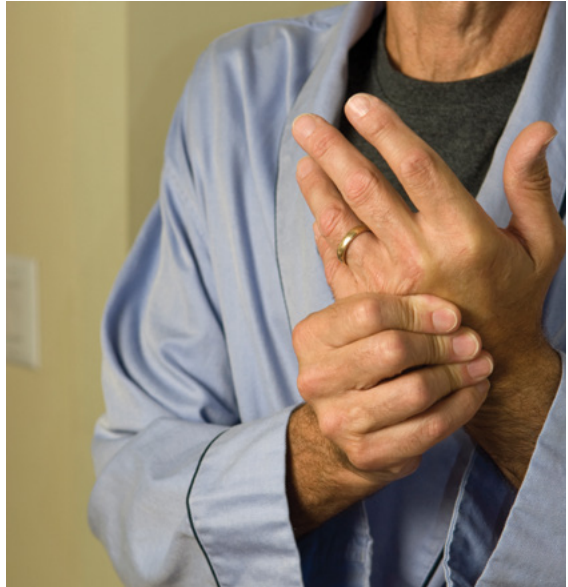
Unusual sensations and weakness

Tumours can cause pressure in the spine and compress (squeeze and press on) the spinal cord. This is called spinal cord compression.

When the spinal cord is compressed, messages (nerve impulses) cannot be transmitted properly to and from the brain.

You might experience weakness or a change in sensation (unusual feelings) in one of your arms or legs or in the lower half of your body. These unusual sensations are called paraesthesia.

The unusual feelings (paraesthesia) that people experience can include numbness, pins and needles, a heightened sensitivity to touch and temperature and pain that is often described as 'burning'. Gentle pressure or touch, such as the feeling of clothing against the skin, might cause discomfort or pain (a medical condition called allodynia) and moderate temperatures can feel extreme. Some people might altogether lose the ability to tell the temperature of water or objects.



Sometimes, it can feel like there is a tight band around the body where the unusual sensations begin.

Worsening numbness, tingling, weakness or paralysis (inability to move) of the arms or the legs should be taken seriously. Sometimes these symptoms can be experienced in both arms as well as both legs. This is a possible sign of a problem in the cervical section of the spine (the neck).

Unusual feelings only affecting the feet are a possible sign of problems with the longest nerves within the peripheral nervous system.

Any type of tumour can cause spinal cord compression, however metastatic (secondary) tumours cause approximately 85% of cases (in every 100 people with spinal cord compression, 85 cases will be caused by a metastatic tumour). This is referred to specifically as metastatic spinal cord compression (MSCC) and is considered a medical emergency. People with breast, lung, prostate or bone cancer are at the greatest risk of their cancer spreading to the spine and causing MSCC. It is crucial that the pressure on the spinal cord caused by the tumour(s) is relieved quickly, to reduce the risk of permanent damage to the cord (see [Possible treatments and Other treatments and approaches sections](#)).

Spinal cord compression can be caused by other problems such as a back injury, an abscess, a slipped disc or other conditions causing inflammation. Your doctors will rule out these other causes of spinal cord compression during the tests and investigations you have.

Bladder or bowel problems

If spinal tumours press on the spinal cord (spinal cord compression) they can cause bladder and bowel problems. People will usually have already experienced unusual sensations or weakness in their legs before bladder or bowel problems develop.

Bladder or bowel problems can include incontinence (a loss of control of bowel movements or passing urine), needing to go to the toilet with increased frequency or urgency, or difficulty emptying the bladder or bowel. You should seek medical attention if you experience these symptoms, especially if your sexual function is also affected.

What causes spinal tumours?

We do not yet know what causes primary spinal tumours and we do not know why some are malignant and some are not.

Secondary (metastatic) spinal tumours are always caused by a cancerous tumour spreading from another part of the body.

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Could I have prevented my spinal tumour?

No. We have not established clear risk factors for spinal tumours in the way that, for instance, smoking has been established as a clear risk factor for lung cancer.

Are there warning signs?

No, there are no warning signs before the onset of symptoms. Some non-malignant tumours grow very slowly over several years and can reach a large size before they are detected. Malignant tumours tend to grow more quickly and will usually have been present for a shorter time when they are discovered.

The onset of symptoms does not tell us how long the tumour has been there or whether it is non-malignant or malignant.

How common are spinal tumours?

Spinal tumours are not common. Secondary (metastatic) spinal tumours are more common than primary spinal tumours. The spine is the third most common site for secondary tumours, after the lungs and the liver. Some studies have estimated that up to 70% of patients with cancer that has spread will have secondary tumours in their spine.

Primary bone tumours in the spine are very rare. They account for just 4.6% of all primary bone tumours, which are themselves a rare group of tumours. In other words, out of every 100 primary bone tumours between four and five of these will be located in the bones in the spine.

Intramedullary spinal cord tumours account for only 2–4% of all central nervous system tumours. In other words, out of every 100 tumours found in the central nervous system (the brain and spine) two to four of these will be located inside the spinal cord.

Are my family at risk?

The hereditary risk of spinal tumours is very low. It is rare for a spinal tumour to be traced to a genetic factor passed on within a family. If one of your relatives has also had a spinal tumour it can almost always be put down to coincidence.

An increased risk does exist with some very rare genetic conditions such as neurofibromatosis and von Hippel-Lindau syndrome.

Tests and investigations

All tests and investigations will be carried out in a local hospital or local neuroscience centre. Your doctor or specialist will refer you for these tests. If you are being treated for cancer in another part of your body and your doctors suspect that your symptoms are caused by the cancer spreading to your spine they will arrange the tests and investigations. They will also refer you to a neurosurgeon or spinal surgeon who specialises in operations on the spine.

If your symptoms have developed very gradually, you are likely to have an outpatient appointment, rather than be admitted to hospital.

X-rays of your spine will provide important information. However, spinal tumours are usually confirmed with the results of an **MRI scan** or a **CT scan** and possibly a **biopsy** or a **bone scan**.

Sometimes, doctors might use the term ‘spinal lesion’ if an abnormality has been found in the spine but they don’t yet know exactly what it is. Although a tumour might be suspected, a spinal lesion could turn out to be an abscess, bleeding or an infection. Doctors will need to do tests before they can confirm a diagnosis.

MRI scan

An MRI scan (magnetic resonance imaging scan) uses strong magnetic fields and radio waves to produce pictures of the spine that are more detailed than a standard X-ray.

During the scan you will lie flat on a bed that slowly moves into a long tube. The scan is painless but the scanner is very noisy. Earplugs or headphones are provided. Some people find the confined space in the scanner tunnel claustrophobic. If you think you will feel anxious or uncomfortable in the scanner tunnel, or experience claustrophobia, you should tell the staff before the scan. You should

also tell them if you unexpectedly feel anxious just before you are due to enter the scanner tunnel. During the scan, the radiographer who controls the scanner will be in another room but you will be able to talk to them through an intercom.

Sometimes a dye (called contrast agent) is injected into a vein in your arm to help show the tumour more clearly in the pictures. The dye may make you feel hot and flushed. This is a very common side effect and will pass quickly.

CT scan

A CT scan (computerised tomography scan) is a special type of X-ray that takes pictures of your spine from different angles.

During the scan you will be asked to lie on a scanner table while the scanner rotates around your body. It is a painless examination, and usually takes 15-30 minutes.

Sometimes a dye (called contrast agent) is injected into a vein in your arm to help show the tumour more clearly in the pictures. The dye may make you feel hot and flushed. This is a very common side effect and will pass quickly.



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(You might be interested in reading our fact sheet, [Brain and spine scans](#), for further information.)

Bone scan

A bone scan is a test used to diagnose tumours or cancer in the bone. For the test, a very small amount of a radioactive chemical (radiotracer) is injected into your vein. A few hours later (once the chemical has had time to move around your body) pictures are taken using a special camera that detects the radiation given off by the chemical. The chemical collects in abnormal bone, so any problems with the bones can be detected in the pictures. The scan itself usually takes about an hour. Only a very small amount of radiation is used and the test is safe.

Biopsy

A biopsy is an operation to remove a small sample of a tumour that can be sent to a pathologist for examination (see [Health professionals section](#)). You might have a biopsy if your doctors are not sure from the results of your scans what type of tumour you have.

Sometimes the biopsy can be performed using a large needle with just a local anaesthetic (the area will be numb but you will be conscious throughout the procedure). This will depend on the size and location of the tumour. Scanning equipment is used to guide the needle. A sample of the tumour is taken via the needle. Usually, you will need to lie face down.

Otherwise, open surgery will be performed under a general anaesthetic. This means you will be unconscious throughout the procedure. A small incision (cut) is made, usually over the back of the spine, to expose the area where the tumour is located. A small amount of the tumour is removed and sent to a pathologist for analysis.

A preliminary diagnosis is often made during the biopsy operation but it might not be confirmed for several days.

Possible treatments

There are different treatment options for spinal tumours and specific treatment pathways will differ for each individual. Your medical team will discuss your best treatment options with you. These options will depend on the type of tumour you have and other factors, such as the size of the tumour, its exact location and which part of your spine is affected. Malignant spinal tumours are usually more difficult to treat than non-malignant tumours.

The specific purpose of the treatment will also differ for individuals. The ultimate aim of treatment is to destroy or remove the tumour altogether, however this is not always possible. All treatments aim to relieve or reduce the risk of pressure on the spinal cord, and the symptoms this can cause.

If you have been introduced to a clinical nurse specialist (CNS), he or she can answer any questions that you, or those who care for you, may have about treatment options and discuss any concerns.

Spinal tumours can be serious and life-threatening. It is not always possible to treat them successfully. Secondary (metastatic) malignant tumours are difficult to treat. The specialist team treating the primary cancer will often take on the responsibility for the treatment of secondary (metastatic) spinal tumours.

If treatment cannot completely destroy a tumour it may still be able to relieve pressure on the spinal cord and prevent any symptoms from getting worse. In some cases it may also reduce any current symptoms.

The four main treatment options for spinal tumours are **surgery**, **radiotherapy**, **radiosurgery** and **chemotherapy**.

Surgery

Surgery is most commonly used to treat non-malignant spinal tumours but it might be used to treat some malignant tumours. The aim of surgery is to remove as much of the tumour as possible without damaging the spinal cord or the nerves surrounding the tumour. Successfully removing all of a tumour increases the chance of a good or full recovery. In some cases it also reduces the risk of the tumour recurring. Surgery is not suitable for everybody. Your medical team will discuss the best treatment options with you.

The operation is carried out under a general anaesthetic which means you will be asleep throughout the procedure and will not feel anything. An incision (cut) is made at the point where it is easiest to reach the tumour. This might be on your back, your neck or your side. Sometimes, the surgeon may also need to remove part of the bone in your spine so that they can access the tumour. This procedure is called a laminectomy.

Often, non-malignant tumours can be removed completely by surgery. However, this is not always possible and, in some circumstances, it is safer to leave a small amount of the tumour behind than to risk causing damage to the spine or nerves. Tumours within the spinal cord (intramedullary tumours) are particularly difficult to treat with surgery and a complete removal of the tumour might not be possible. The neurosurgeon will remove as much of the tumour as they judge to be safe. The partial removal of a tumour is called debulking.

Spinal tumours in the bone can be very difficult to remove with surgery. Often, the difficulty is a combination of the size of the tumour, accessing it (tumours in the bone can extend around the spinal cord from the front to the back of the spine) and preserving the stability of the vertebrae (spinal bones). In some cases, the spine will need to be strengthened by a metal support to prevent the bone

collapsing and causing spinal cord compression. This technique is usually referred to as 'instrumentation' or 'stabilisation'. In other cases, the bone may have already collapsed and be compressing the spinal cord. If this has happened, the surgeon will remove part of the bone to release the spinal cord and replace it with a support structure called a cage. This will also be done if you have had bone removed in a laminectomy.

During spinal surgery, it is possible for there to be a leak of CSF (cerebrospinal fluid – the fluid that surrounds the brain and spinal cord). If this happens, you may find that you wake from surgery with a bad headache. This side effect can usually be treated by doctors with fluids and painkillers.

Even if the complete removal of a spinal tumour is not possible, the partial removal of the tumour (debulking) can relieve pressure on the spinal cord. This can increase the chances of people recovering from weakness and paralysis. You might be referred for radiotherapy and/or chemotherapy after your surgery to treat the remaining tumour cells. This is more likely if you have a malignant tumour.

Spinal tumours and surgery to treat them can cause damage to the supporting structures of the spine. This results in weakness and instability and allows abnormal movement of the spine which can cause further damage to the spinal cord and nerves. To help provide support and stability, some people have metal supports implanted into their spine at the time of their surgery. Some people might also wear an external brace or reinforced jacket after their surgery to provide extra support while they are recovering strength and stability.

Radiotherapy

Radiotherapy is often used to treat malignant tumours and tumours that can't be reached safely with surgery. It might also be used after surgery to try to treat any tumour cells that couldn't be removed. If you have had surgery, you will be given time to recover and for your wounds to heal before receiving radiotherapy treatment.

Radiotherapy uses X-rays and gamma rays to damage or destroy the tumour. The treatment slows down tumour growth and lengthens the time before it regrows. In some circumstances, radiotherapy can destroy the tumour completely.

Radiotherapy treatment is planned and carried out by a radiotherapist who might also work with an oncologist (a doctor who specialises in cancer). It is likely that your radiotherapist will have a specific interest in tumours of the central nervous system (the brain and spinal cord). They will explain and discuss the radiotherapy treatment with you and talk through any worries or concerns you might have.

Radiotherapy will not always be available at the same hospital where neurosurgery is carried out but there is always a close link between the hospitals providing your treatment.

The exact method of radiotherapy treatment will differ for each individual depending on factors such as the type of tumour, its size and location. The specific purpose of the treatment might also differ for individuals. For example, to relieve pain, someone might be given a single dose of radiotherapy. To completely destroy a tumour, someone might require daily radiotherapy over a course of several weeks.

Side effects of radiotherapy include temporary worsening of the existing symptoms and inflammation of the skin, similar to sunburn.

Most people feel tired towards the end of their course of radiotherapy. Other side effects can include bone fractures and bone marrow suppression (radiotherapy can slow down the cells in the bone marrow that produce new blood cells).

Radiosurgery

Similarly to radiotherapy, radiosurgery might be used as a treatment when surgery is not possible or as an additional treatment after surgery. Despite its name, the treatment is not a surgical procedure and does not involve any incisions (cuts). It works by targeting a high dose of radiation at the tumour in order to damage and destroy the tumour cells. The treatment is delivered by a machine called a linear accelerator (LINAC) or gamma knife.

The LINAC machine uses one beam of radiation which arcs around a single point, treating that specific area but not affecting the surrounding tissue. The gamma knife uses hundreds of relatively weak energy beams all aimed at the tumour from different angles. The tumour receives the full dose of radiation where all the beams meet but the surrounding healthy tissue is not damaged.

Unlike radiotherapy, which might require several sessions over weeks and months, radiosurgery is completed in one to five sessions and does not require an overnight stay in hospital. People can return to their normal routine immediately after the treatment without experiencing any of the side effects of surgery or radiotherapy.

It can take a long time for radiosurgery treatment to work and tumours might slowly shrink in size over months and years.

Radiosurgery for treating spinal tumours has previously only been available in a few specialised centres in the UK. However, under NHS England plans, each region in England will soon have its own radiosurgical service.

Radiosurgery is not suitable for everyone and your doctor will discuss your best treatment options with you.

Intensity modulated radiotherapy (IMRT) is a newer form of very precise radiation treatment carried out with the LINAC machine. Energy beams of varying strengths (modulated beams) and three-dimensional scans are used to focus the radiation on the specific shape of the individual tumour, minimising damage to the surrounding healthy tissue.

Chemotherapy

Chemotherapy is the use of drugs to destroy tumour cells. There are different types of chemotherapy. Some chemotherapy drugs are taken by mouth and others are given via a drip into a vein. Chemotherapy is mostly used for people with secondary (metastatic) spinal tumours.

A course of chemotherapy is usually prescribed by an oncologist (a cancer specialist) who has expertise in both radiation and chemotherapy. A course of chemotherapy is made up of a number of 'cycles'. A cycle refers to a treatment session and the break that separates it from the next treatment session. The length of your course of chemotherapy (the number of cycles) will be designed specifically for you based upon the type of tumour you have.

The possible side effects of chemotherapy vary considerably depending on the particular drug used. They include nausea (feeling sick), vomiting (being sick), tiredness, hair loss and a reduced resistance to infection. You should discuss these possible side effects with the specialist providing your treatment.

Chemotherapy will not be suitable for everyone.

Other treatments and approaches

Steroids

Steroids are used to reduce swelling in the spine. This helps to relieve pressure on the spinal cord and nerves and reduce the risk of any permanent damage to the spinal cord. Steroids are usually given alongside radiotherapy or surgery. You will usually have to continue taking steroids for a while after your radiotherapy or surgery.

Steroids are more likely to cause side effects the longer you have been taking them. Symptoms can include increased appetite, weight gain, indigestion, acne, stretch marks, muscle weakness, diabetes, sleep disturbance and feeling restless or agitated. For most people, these side effects go away when the steroids are stopped. It is very important that you take your steroids exactly as your doctor has instructed; it can be dangerous to suddenly stop taking steroids.

Steroid tablets can irritate the lining of the stomach and increase the likelihood of getting stomach ulcers. You might be given anti-ulcer drugs to reduce the risk. You might also be given an antacid drug either in liquid or tablet form.

Pain-relief drugs

For people with spinal tumours, pain-relief drugs are used mainly to control back or neck pain. They might be combined with other drugs to control nausea (feeling sick) and vomiting (being sick). If a morphine-based drug is used it might be combined with a drug to reduce the risk of constipation, which can be a side effect. There are many different types of pain-relief drugs and your doctors will try to give you the most suitable and effective one for your situation.

Orthotics

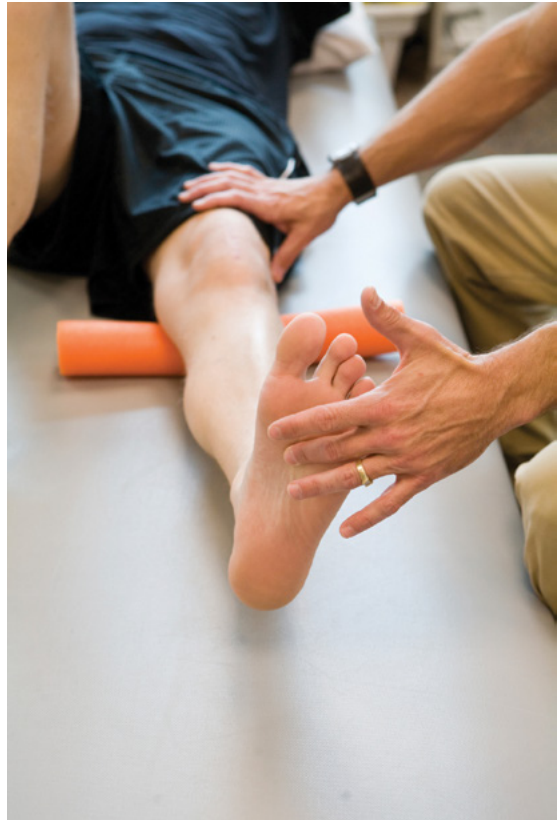
Orthotics services use external devices to support and improve posture and mobility and to manage pain.

If a spinal tumour is causing a mal-alignment of the spine (pushing spinal bones out of their normal position) it can cause a great deal of discomfort. To prevent any further mal-alignment, your doctor may advise that you are fitted with a back brace or cervical (neck) collar. These devices work by holding the spine in a certain position which helps to relieve pain and encourages the vertebrae (spinal bones) to heal in a good position whilst you are undergoing treatment.

These devices are usually fitted by a specialist called an orthotist. In some hospitals, specially trained nurses and therapy staff are also able to fit them for you.

Physiotherapy

If you have weakness in your arms or legs, physiotherapy exercises can help to improve your strength, co-ordination and balance. The aim of physiotherapy is to maximise the speed and extent of your recovery after your main treatment, to help you live as independently as possible. Even if you are experiencing complete paralysis of an arm or leg, exercise and movement is important. Keeping moving will help avoid stiff joints and spasticity (muscle spasms) or muscle contractions.



Sometimes, special techniques can be used to compensate for paralysis. These techniques assist particular movements and can help promote mobility and independence (for example, techniques to assist getting in and out of bed or using a wheelchair).

Paralysis of the arms or legs, or a significant loss of strength and movement, can increase the risk of spasticity (muscle spasms) and stiffness. People can find it difficult to move their legs and sometimes find that their legs jump or twitch in bed. Different drugs are available to help reduce stiffness and muscle spasms (for example, baclofen or Botox injections). These drugs can improve mobility and comfort, especially when combined with regular gentle exercise to stretch the affected muscles.

Occupational therapy

An occupational therapist can give advice on everyday activities such as washing, dressing, cooking, eating and using equipment around the home. The aim is to help people live as independently as possible. They can also give practical advice for people in their workplace.

Sometimes, a small piece of equipment or minor adaptation is all that is required to make someone's everyday life easier. For example, access problems can often be overcome with alterations such as ramps and handrails.

Bladder and bowel management

If you have problems controlling your bladder, you might require a urinary catheter. This is a tube inserted into the bladder to drain away urine. Your doctors and nurse specialists can advise you if they think a urinary catheter would be helpful to you.

People with bladder problems often also have problems with the function of their bowel. It might be that your bowel can be retrained to ensure regular motions. Your doctor or nurses can advise you.

Skin care

Any areas of the body with numbness or a loss of feeling are susceptible to pressure sores because the person will not feel any points of pressure when they are sitting or lying in bed.

If someone is experiencing severe numbness or loss of feeling, they should be turned frequently in bed to change their position and prevent pressure sores. It is important to keep the skin clean and dry. This sort of nursing care can be demanding and it might be difficult to carry out at home. Specially designed beds and support cushions are available to help prevent pressure sores. These can make home care easier. If someone is experiencing a loss of temperature sensation it is important to take care to avoid burns from bath water that is too hot.

Complementary therapies

Some people find that complementary treatments and therapies such as acupuncture, massage, hydrotherapy, aromatherapy and reflexology are helpful. Doctors would usually only recommend using these treatments and therapies alongside conventional medical treatments rather than as a substitute for them. You should always check with your doctors or nurses that these therapies are safe to use alongside your main treatment.

Complementary treatments and therapies are unlikely to provide specific treatment for your tumour but they might help to improve your general wellbeing.

Watch and wait

The 'watch and wait' approach is most commonly used for non-malignant tumours. It is used in circumstances where other possible treatments risk causing more harm than doing nothing.

As the name suggests, the approach involves carefully monitoring the tumour without actively trying to treat it. You will have regular scans and check-ups with your specialist to keep a close eye on your condition. However, no treatment will be started unless your tumour grows, becomes more aggressive (starts to grow faster) or your symptoms get worse.

Living with a spinal tumour without receiving any targeted treatment for it can be a very frightening prospect. It might help to use this time to learn more about the treatments options that may become available to you further down the line, before you have to make any decisions. You might also like to spend some time talking with your friends and family about these options. Being better informed and prepared may help you to feel more in control.

Clinical trials

Sometimes there is the opportunity for people with spinal tumours to take part in clinical trials as part of their treatment. Clinical trials test new treatments on patients and compare the results with standard treatments. Patient participation in clinical trials is voluntary. Your medical team can discuss any clinical trial options with you and answer any questions you might have about taking part.

(You might be interested in reading our fact sheet, *Clinical trials*, for further information.)

Recovery

The extent of the recovery you might make will depend on factors such as the type of spinal tumour you have, to what extent it has spread in your spine and whether you are experiencing severe symptoms like paralysis.

The spinal cord and nerves are often slow to recover if they have been severely compressed for a prolonged length of time and are badly injured. Most people find that the longer they experience complete paralysis, the less likely recovery of feeling and movement becomes.

Fatigue

People often experience tiredness or fatigue (severe tiredness) after serious illness, especially if they have undergone surgery or treatments like radiotherapy and chemotherapy. For some people this will pass after a few weeks. However, people with spinal tumours can experience longer-term fatigue.



You might find that you become exhausted even after everyday activities like getting washed and dressed, going to the shops, watching television or talking with friends. Taking regular breaks can help. Try to do this at least three times a day for around 20-30 minutes. Listening to your favourite music might be helpful, but try to avoid anything too stimulating like watching television or reading.

It can help to have a daily routine. Try to get up and go to bed at regular times each day. Plan and pace your activity throughout the day and try to balance activity with relaxation breaks. If you return to work, you could talk to your employer about the possibility of being given time for some extra breaks during the working day.

More information on managing fatigue can be found on the Brain & Spine Foundation website.

Practical support

There are a number of organisations that help people affected by spinal tumours and other forms of cancer. The most well known are the Macmillan Cancer Support teams and the hospice movement. These services are available throughout the country. They deal mainly with people affected by malignant tumours. If you feel that you might need the type of support they offer, you can discuss this with your GP or the specialist team looking after you.

Alternatively, Maggie's Centres are places that offer practical, emotional and social support to people affected by any type of cancer. Patients and families can drop-in for free support and advice or even just for a chat. There are 19 centres across the UK, all of which are located within the grounds of NHS hospitals ([see Useful contacts](#)).

If you are feeling depressed or worried while staying in hospital or attending an outpatient appointment, you should feel free to speak to the specialist cancer nurse attached to your medical team. He or she will be able to answer your questions, offer support and refer you to an appropriate counselling service, if this is what you want.

If you are having, or think you might have, financial problems because of the impact on your ability to work, you might be eligible for several different payments. It is likely that a social worker is attached

to the unit where you are receiving your treatment. Whatever your situation, it could be helpful to talk to them as soon as possible. It might also be helpful to talk to your local Citizens Advice Bureau for advice on what financial support is available to you.

Emotional support

Being diagnosed with a spinal tumour is very distressing and lots of things in your life may change as a result. You might feel low, tearful, angry or anxious. It is natural to feel shocked about your situation and to feel uncertain about the future. Many people worry about dying. It is normal to worry about this but questions about dying are very difficult to answer. Spinal tumours can make you very ill but they can often be controlled successfully for a period of time.

It can be hard to express and explain to others how you feel and the worries you have. This can lead to feelings of isolation. It often helps if you can talk to a friend or relative about how you are feeling rather than keeping your feelings bottled up inside.

If you find it difficult talking to your friends or family, you might find it easier to talk to an independent person, such as a counsellor or someone on a helpline. You might like to talk to your clinical nurse specialist (CNS), if you have been introduced to one. As well as offering information and support to you and your family and answering your questions, he or she can also refer you to an appropriate psychological service, such as a counsellor.

Everyday activities

Returning to everyday activities after illness is very important for many people. The activities you are able to return to, and how quickly you can return to them, will depend on the speed and extent of your recovery. This will be different for everyone. Persistent symptoms (weakness, paralysis, bladder and bowel problems) and instability of the spine can make it harder to return to certain activities.

Although you may want to return to your normal routine as soon as possible, you are likely to get tired more quickly. If you feel tired you should rest; it is important to listen to your body to avoid overexerting yourself.

Can I drive?

Having a spinal tumour might affect your right to hold a driving licence, depending on the symptoms you are experiencing. If you have any problems with your spine which affect your ability to drive safely, you are obliged to notify the Driver and Vehicle Licensing Agency (DVLA) about your condition and you must not drive until you have DVLA approval. (For the DVLA's contact details, see page 35.)

The DVLA will assess each case on an individual basis. The regulations for safe driving include basic strength and control of the arms and legs for steering and other vehicle controls, and basic movement of the neck and shoulders to turn in order to see out of side and rear windows. The DVLA will use the information you give them in a medical questionnaire to make their decision. If necessary, they will also liaise with your GP or specialist.

People with certain symptoms might be permitted to drive with specific modifications made to their vehicle. For example, someone

with weakness in their legs might have hand controls fitted to their vehicle. Someone with weakness only in their left leg might drive an automatic car. The DVLA can advise on vehicle modifications.

Regulations are stricter for people who have HGV (heavy goods vehicle) and PSV (public service vehicle) licences.

Can I fly?

Yes. There is nothing to stop you travelling by air unless you have serious neurological symptoms caused by a spinal tumour. If you have paralysis, the practicalities of air travel, especially getting on and off the aeroplane, might be difficult. Also, people with mobility problems can find the confined space of an aeroplane difficult. For example, getting up to use the toilet can be very difficult.

Can I play sport?

You should ask your doctor or specialist for individual advice. All contact sports such as rugby or martial arts should probably be avoided even after a full recovery. If your tumour affected the bones in your spine you should avoid any heavy weight training.

You might be able to swim once any wounds have healed and you have recovered strength and stability in your spine. Certain swimming strokes might not be appropriate depending on your individual situation.



Can I have sex?

Yes, you can have sex as soon as you feel ready. Women are advised not to become pregnant during their recovery as this can cause stress and strain on the back and supporting muscles.

When can I go back to work?

Being diagnosed with a spinal tumour does not mean that you have to give up work, although you will need to take time off during your treatment and recovery. This might mean you are unable to return to work for a long period of time.

The timing of your return to work will depend on what sort of work you do. For example, you might need to wait for the renewal of your driving licence or for adaptations to be made to your vehicle. Physical work might no longer be possible.

As recovery differs for each individual, the general advice is to use your common sense and only return to work when you feel able. You might find it helpful to discuss this with your doctors or nurses. You could also talk to your employer about how they can help support you back into work. Many people return to work on a part-time basis before returning full-time.

Most people find that returning to work is a positive part of their rehabilitation and a big step in getting back to their normal lives.

Health professionals

Clinical nurse specialist (CNS): a nurse who specialises in a particular condition or conditions, for example, neuro-oncology. A CNS will often be the main point of contact between a patient and the rest of the medical team treating them.

Counsellor: a person trained to give guidance on personal or psychological problems.

Neurologist: a doctor who specialises in the diagnosis and treatment of people with neurological conditions.

Neurophysiotherapist: a physiotherapist who specialises in treating people with neurological conditions. A neurophysiotherapist assesses, plans treatment and treats people with physical and mobility problems.

Neuroradiologist: a specialist doctor who performs, reads and reports on scans, such as CT scans and MRI scans.

Neurosurgeon: a specialist doctor who performs brain and spine operations.

Occupational therapist: a specialist health professional who offers practical support and advice on everyday skills and activities, such as washing, cooking and using equipment at home.

Oncologist: a doctor who specialises in the diagnosis and treatment of people with cancer.

Pathologist: a doctor who specialises in the causes, effects and behaviour of diseases.

Radiographer: a specialist trained to control the equipment used for scans, such as CT scans and MRI scans.

Radiotherapist: a doctor specially trained to use radiation for the treatment of cancer and other conditions.

Useful contacts

Spinal tumours:

Brain & Spine Helpline

Brain & Spine Foundation

LG01 Lincoln House

Kennington Park

1-3 Brixton Road

London SW9 6DE

Helpline: 0808 808 1000

helpline@brainandspine.org.uk

www.brainandspine.org.uk

Run by neuroscience nurses, providing support and information on all aspects of neurological conditions for patients, their families and carers and health professionals.

Spinal Cord Tumour Forum

www.spinalcortumour.org.uk

info@spinalcortumour.org.uk

Online support and information on non-malignant spinal cord tumours.

Spinal Injuries Association

SIA House

2 Trueman Place

Oldbrook

Milton Keynes MK6 2HH

Helpline: 0800 980 0501

www.spinal.co.uk

sia@spinal.org.uk

Support and information on spinal injuries and paralysis.

BASIC (Brain And Spinal Injury Centre)

554 Eccles New Road

Salford M5 5AP

Helpline: 0870 750 0000

www.basiccharity.org.uk

enquiries@basiccharity.org.uk

Support and information on neurological conditions.

The Brain Charity

Norton Street

Liverpool L3 8LR

Tel: 0151 298 2999

www.thebraincharity.org.uk

info@thebraincharity.org

Support and information on neurological conditions.

Cancer Research UK

Angel Building

407 St John Street

London EC1V 4AD

Helpline: 0808 800 4040

www.cancerresearchuk.org

Provides information on cancer and funds research.

Macmillan Cancer Support

89 Albert Embankment

London SE1 7UQ

Helpline: 0808 808 0000

www.macmillan.org.uk

Support and information on cancer.

Maggie's Centres

Various locations across the UK

Tel: 0300 123 1801

www.maggiescentres.org

enquiries@maggiescentres.org

Face-to-face support for anyone affected by cancer.

Bladder and bowel problems:

Bladder and Bowel Community

7 The Court

Holywell Business Park

Northfield Road

Southam CV47 0FS

Tel: 01926 357220

www.bladderandbowelfoundation.org

help@bladderandbowelfoundation.org

Support and information on bladder and bowel problems.

Driving:

Driver and Vehicle Licensing Agency (DVLA)

Drivers Medical Group

Longview Road

Swansea SA99 1TU

Tel: 0300 790 6806

www.dft.gov.uk/dvla

www.direct.gov.uk/motoring

Information on medical rules for drivers.

General health:

NHS Choices

www.nhs.uk

NHS non-emergency number: 111

Medical advice and information on health services.

Support groups

The Brain & Spine Foundation's online discussion forum offers the opportunity to post messages, exchange views, ask questions and share experiences with other people affected by neurological problems.

www.brainandspine.org.uk/forum

The Spinal Cord Tumour Forum website has a message board where you can read messages, post replies or start new topics of discussion.

www.spinalcordtumour.org.uk

Further reading

The Brain & Spine Foundation produces fact sheets with information on brain and spine scans and clinical trials. These fact sheets can be viewed online or downloaded free of charge.

References

Details of the medical references used for this booklet are available at www.brainandspine.org.uk/references or on request from the Brain & Spine Helpline: 0808 808 1000.

Thank you

We would like to thank everyone who contributed to this booklet, especially Ian Sabin (Consultant Neurosurgeon), Amy MacNeil (Clinical Nurse Specialist for complex spinal surgery) and Jorge Chacon Cordero (Clinical Nurse Specialist for complex spinal surgery).

Brain & Spine Foundation

Our mission is to improve the quality of life of people affected by neurological problems by providing expert information, support and education. We rely on donations to provide our services to anyone who needs us.

How to donate

- Online: www.brainandspine.org.uk/donate
- By phone: 020 7793 5900
- By post: send a cheque to the address below

Contact us

Brain & Spine Foundation
LG01 Lincoln House, Kennington Park, 1-3 Brixton Road,
London SW9 6DE

Telephone (switchboard): 020 7793 5900
info@brainandspine.org.uk

Helpline: 0808 808 1000
helpline@brainandspine.org.uk

Registered charity number: 1098528

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Published: May 2017

Next review date: May 2020

www.brainandspine.org.uk

ISBN 978-1-901-893-71-7



ISBN 978-1-901-893-71-7

