

Understanding bone metastases and lung cancer



Introduction

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

We have written this 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.

Not every section of this booklet may apply to you, so use the index and the support of your lung cancer doctors and nurses to go straight to the parts you need to know. Use this booklet along with information provided by your healthcare team.

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

We hope that this booklet answers most of your questions about bone metastases. If you would still like to talk to someone about lung cancer, call our free and confidential **Ask the nurse** service on: **0800 358 7200** or email: lungcancerhelp@roycastle.org



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.



Amgen has funded the development of this booklet but has had no input on the content.

Contents

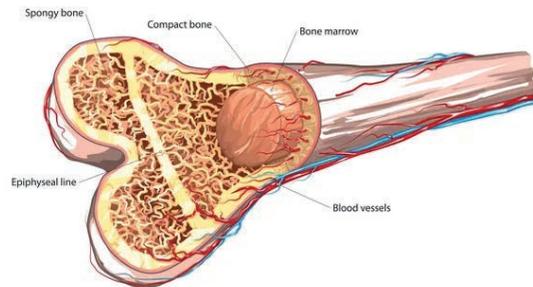
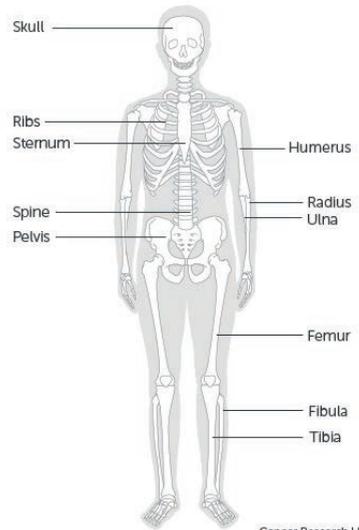
○ About the bones	4
○ How does cancer start?	5
Primary cancer	6
Secondary cancer	6
○ Secondary cancer affecting the bones	8
How do bone metastases affect people?	9
○ Managing bone metastases	11
Keeping active	11
Managing pain	12
○ Treating bone metastases	15
Radiotherapy	18
Medicines to reduce symptoms	20
Surgery	22
○ Metastatic spinal cord compression (MSCC)	24
○ What other support can I get?	28
○ Other things to think about	35
○ Questions to ask your doctor or nurse	42

About the bones

There are more than 200 bones of different shapes and sizes in the human skeleton. The longest is the thigh bone (*femur*) and the smallest is the 3mm long bone in the inner ear called the stapes.

Bones form a rigid supportive framework for the body. We are able to move because muscles, tendons and ligaments attach to bones across joints, such as the knee, hip and elbow. Some bones meet in joints that don't move.

Other bones give protection to the body's internal organs. The skull, for example, protects the brain, and the ribs protect the heart and lungs in the chest.



As you can see in the diagram, bones are made up of different structures. Compact bone is the hard, outer layer that is dense, strong and durable.

Inside there is spongy (*cancellous*) bone that is made up of rod-like structures. It is lighter, less dense and more flexible than compact bone.

Bone is made up of soft connective tissue and minerals such as calcium. It is the calcium that hardens the bones. Throughout these tissues are the bone cells themselves, working together to maintain the shape, strength and health of the bones.

Although bones are hard, they are not static tissue. They need to be constantly maintained. There are three main types of bone cell involved in this:

- osteoblasts – these are responsible for making new bone and repairing old bone
- osteocytes – these are inactive osteoblasts that have become trapped in the bone they created
- osteoclasts – these cells break down bone

Inside almost all bones where there is spongy bone, there is also bone marrow. The marrow is responsible for making millions of red blood cells that transport oxygen around the body in the bloodstream, and white blood cells, or *lymphocytes*, that are involved in the immune system.

Bones also help to balance the body's calcium level by forming more bone or breaking it down.

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 the *primary tumour* or *primary cancer*. Cancer can affect any part of the body, including, for example, the liver, the skin, the lungs, the brain or the bones.

As the cancer grows, it can affect surrounding normal tissue by pressing on it, damaging it or even growing into it. Primary bone cancer is quite rare with only around 550 cases in the UK each year.

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 cancer spreads in this way, the new tumour is called a *metastatic* or *secondary* tumour. These tumours can then begin to grow in the same way as primary tumours and affect surrounding tissue.

Your medical team will use the results of all your tests to *stage* your lung cancer. Staging is a way of describing the size and spread of cancer. It is complicated, but your doctors will explain it as it applies to you.

When you are first diagnosed, a team of healthcare professionals, known as a *multidisciplinary team (MDT)*, will talk about your case to work out the best treatment options for you based on this staging. This will include any treatment for your bone metastases.

From then on, or if your bone metastases have developed later, the MDT will not usually be involved. The cancer doctor in charge of your care will normally be the person who considers your bone metastases and other treatment options and speak to you about what may be best for you.

Doctors classify four stages of lung cancer based on what's known as the TNM system¹. In this system, 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, 1a, 1b or 1c) refers to any spread of the cancer to other parts of the body (*metastasis*).

The combination of numbers and letters means the extent of a person's lung cancer can then be generally grouped into one of the four stages:

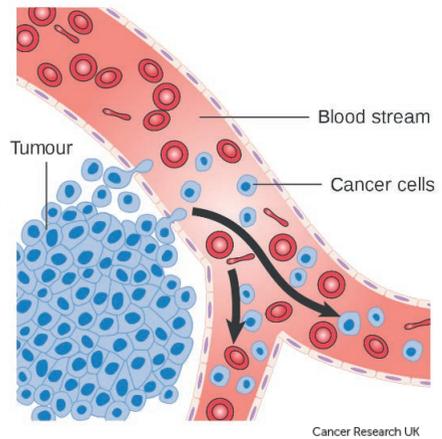
- Stage I (including subgroups IA1, IA2, IA3 and IB) means the cancer is small and in one area of the lung (*localised*).
- Stage 2 or 3 (including subgroups 2A, 2B, 3A, 3B and 3C) cancers are larger and may have spread into surrounding tissues. There may be cancer cells in the lymph nodes (*locally advanced*).
- Stage 4 (including subgroups 4A and 4B) means the cancer has spread to another part of the body (*secondary or metastatic cancer*).

¹Based on the international Association for the study of Lung Cancer's 8th Edition of the TNM Classification for lung Cancer (www.iaslc.org)

Secondary cancer affecting the bones

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

Secondary bone cancer is not the same as cancer that starts in the bones (a *primary* bone cancer). Secondary bone cancer is more common than primary bone cancer. So, someone with primary lung cancer that is affecting their bones has *secondary* bone cancer, or *metastatic* lung cancer to their bones.



Cancer cells spreading into the blood

Lung cancer bone metastases commonly affect the ribs, the spine and pelvis. This may be because they are near the lungs, so are close to the primary tumour, and these bones have a good blood supply.

When osteoblasts and osteoclasts are working properly, new bone is always forming and old bone is dissolving. Cancer cells can interfere with how the bone cells work.

Sometimes the cancer cells cause osteoblasts to make new bone without breaking down old bone first. Although this makes some areas of bone harder (*osteoblastic* or *sclerotic* lesions), the bone is not normal and can break more easily than normal bone.

Other cancer cells affect the osteoclasts leading to bone being broken down without new bone being made. These weaker areas of bone (*osteolytic* or *lytic* lesions) can cause bone to break easily. This is most commonly the case with lung cancer bone metastases.

If you didn't already know you had lung cancer, your healthcare professionals will have needed to carry out tests to be sure you have secondary rather than primary bone cancer. This is important because these cancers are treated differently. You may need further tests, including CT scans, to check if any treatment is being effective, or if your doctors think your cancer is changing or appearing elsewhere.

Your hospital team will talk to you about which tests are best for you. They will make sure you know what will happen on the day, anything you need to do to prepare for the tests, and if there are any risks to you if you have them.

How do bone metastases affect people?

Bone metastases may have been found at the same time as your lung cancer, or they may have appeared later. Not all bone secondaries cause symptoms, but they can affect people in different ways, including:

- pain – the pain can be continuous, people often describe it as gnawing, and it may be worse at night
- backache that gets worse despite resting
- weaker bones that break more easily (a broken bone may be the first sign that your lung cancer has spread)
- raised blood calcium (*hypercalcaemia*) that, if untreated, could lead to dehydration, confusion, vomiting, abdominal pain and constipation
- low levels of blood cells – blood cells are made in the bone marrow and can be crowded out by the cancer cells, causing lowered red blood cells (*anaemia*), increased risk of infection, bruising and bleeding
- pressure on the spinal cord, known as *metastatic spinal cord compression (MSCC)*, that can cause progressive and serious symptoms if not treated (see page 24)

Remember that aches and pains are common and may be a muscle strain or an everyday ache. Tell your doctor if you have a new pain. They can check what is causing it and treat it as soon as possible if necessary. This helps to avoid further problems such as bone fractures or severe pain.

It is rare for someone to go to their doctor with bone pain, or even a fracture, that is due to an undiagnosed lung cancer. However, it does happen. If it has happened to you, it is likely to have been a big shock. Your doctors and nurses will make sure you get plenty of information and support. They will be able to answer any questions you may have.

Having bone 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 already have spoken to you about being prepared for the news that you have secondary bone cancer. However, this doesn't necessarily make it any easier for you.

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.

I am taking what control I can by trying to eat healthily, exercise within my limitations and make the most of each day.

Heather

Managing bone metastases

Metastatic lung cancer is something that can be treated but not cured, and treatment and care options are primarily about managing symptoms and improving your quality of life. As well as possible treatment options (described below), it is important to think about keeping active. Be sure you inform your doctors about any pain so that it can be managed.

Keeping active

Physical activity can benefit people at all stages of their cancer journey. Keeping active can improve survival rates, help maintain quality of life, improve sleep and have mental health benefits. It can also reduce fatigue and risk of falls.

While exercising may feel like something to avoid due to worries about pathological fractures (where the broken bone is caused by the cancer, not by an injury), stopping all exercise can have unwanted consequences. Over time, it can noticeably reduce your strength, limiting how well you can move around and do things and increasing the chance of falls. Muscles can shrink with underuse (*muscle atrophy*), and, with less use, bones can weaken.

Any exercise programme leading up to, during or after treatment, will be unique to you. It will be based on where your bone metastases are as well as how your lung cancer and any other health conditions are affecting you. While some exercises and sports are high-impact or weight-bearing and may put too much stress on your bones, other exercises that are low impact and non-weight bearing, such as swimming, may work well for you.

Physiotherapists, clinical and medical oncologists and occupational therapists will manage any exercise and rehabilitation programme.

The British Lung Foundation run breathing, exercise and singing groups that you may find helpful. Find out if there is one near you at:

- www.blf.org.uk/support-in-your-area

Managing pain

While having cancer does not always mean having pain, it may well develop and be part of how things are for you if you have bone metastases. There are many different medicines, different ways to take the medicines, and non-drug methods that can help relieve it.

Pain can affect all parts of your life. You might not feel able to take part in your normal day-to-day activities. You may have trouble sleeping and eating. You may be irritable with people you love or are close to you. It's easy to get frustrated, sad, and even angry when you're in pain, isolated or alone.



Types of cancer pain

The type of pain you have determines the most effective treatment. You may notice your cancer pain change throughout the day:

- *Acute* pain can be severe and usually only lasts a fairly short time. It's most often a sign that the body has been injured in some way. This pain generally goes away as the injury heals.
- *Chronic* or *persistent* pain lasts for long periods of time (longer than three months). It can disrupt your life if it's not well treated. It may range from mild to severe. Chronic pain doesn't go away but it can usually be controlled by taking pain medicines at regular intervals.

People with pain that's mostly controlled by medicine may also experience *breakthrough* pain:

- *Breakthrough* pain is a flare up of pain that happens even though you are taking pain medicine regularly for chronic pain. It's called breakthrough pain because it "breaks through" the pain relief you get from the regular pain medicine.

Breakthrough pain isn't controlled by your regular doses of pain medicines. It can vary in intensity and be hard to predict. It can come on quickly, last as long as an hour, and feel much like chronic pain only worse – more severe or intense. It can happen several times a day.

Some people have breakthrough pain during a certain activity, like walking or dressing. For others, it happens unexpectedly without any clear cause. It's also very important to manage this type of pain.

Don't just accept pain as a normal part of having cancer. All pain can be treated, and most pain can be controlled or eased. With the right treatment, you will sleep and eat better, enjoy being with your family and friends, and continue with other everyday activities.

While pain can cause distress and discomfort, describing it to your doctor can give them clues to help them manage your cancer:

- Where is the pain?
- Does the pain spread anywhere?
- How would you describe the pain? For example, sharp, gnawing, sudden or hot?
- What makes the pain better?
- What makes the pain worse?
- Does the pain interfere with your ability to move? If so, what movements or activities make it worse?
- Is the pain worse at night? Does it wake you up?

Speak to your lung cancer nurse specialist, cancer doctor or GP about your pain so it can be addressed. There are specialist pain teams in hospitals and in the community who can work with you to manage your pain.

I had greater pain when I was first diagnosed and treated. I took gabapentin and morphesic, and was encouraged to use oramorph as and when I needed it.

Heather

Treating bone metastases

There are a number of treatment options and these vary depending on a range of factors. Treatments offered may:

- improve pain
- shrink the tumours
- slow the tumours' growth
- prevent or control other symptoms

You may decide to go ahead with treatment options you are offered. Many treatments have side effects though these may be managed and outweighed by some of the outcomes above. These outcomes may mean you can continue to enjoy a good quality of life and do many of the things you want to do.

Choosing not to have any treatment for bone metastases doesn't mean you would not receive other treatments to maximise your quality of life, such as medicines to manage any pain.

This is entirely your decision, and it may not be an easy one. Talk things through 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.

This section will help you think about what you want to do next and tells you a bit about some of the treatments options for bone metastases that may be available to you. These include:

- radiotherapy
- medicines to reduce symptoms
- surgery
- clinical trials

Your doctor may recommend more than one type of treatment. While these treatments help manage your bone metastases, you may also receive other treatments for lung cancer.



As with many illnesses, there are several possible treatment options. 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.

When talking to you about your treatment options, your medical team will take into account the outcomes of any scans and X-rays and other tests you may have had.

These will show the size and location of the cancer. They will also consider your general health and medical history. Some of the more likely options, along with some possible 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 specialist. 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.

Some things you can ask your doctor about treatment options to help you make your decision:

- What is the likelihood that the treatment will help me feel better?
- If the treatment works, when should I start to feel better?
- What is the best I can expect if the treatment works well?
- Is the treatment more about my quality of life than helping me to live longer?
- What side effects can I expect?
- Can the side effects be prevented and how can I manage them better?

Ask your cancer doctor or lung cancer nurse specialist to go through things again with you so you are clear with what they are telling you. If you are unhappy with the treatment and care options you are being offered, you may decide to ask for a second opinion.

My lung cancer nurse specialist has helped me to navigate my way through all the various appointments, meetings, treatments and all the other aspects of a cancer diagnosis.

They have been a helpful link for me and a great point of contact if I have had any questions.

Heather

Radiotherapy

Radiotherapy is a treatment that uses high energy X-rays to kill cancer cells and is the most common, and usually effective, treatment for painful secondary bone tumours.

Your radiotherapy treatment will be given by a machine called a *linear accelerator*, known as a *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, usually done at an outpatient appointment.

Often, people get only one treatment though others may receive a series of treatments over a couple of weeks. Treatment depends on the size and location of the treatment site and the aim of the treatment.

The benefits of radiotherapy depend on a number of factors. 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 genes of cancer cells that tell cells what to do. This damage causes cancer cells to stop dividing and can stop the tumour from growing or may even cause it to shrink.

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

Radiotherapy doesn't shrink cancerous tumours immediately. It can take days or weeks for cancer cells to start to die. The cells can keep dying for several weeks after the treatment ends. It can take some time for you to notice the beneficial effects.

The 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. In addition, 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.

If you are worried about how you are feeling after treatment, speak to your cancer doctor or lung cancer nurse specialist.



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

Medicines to reduce symptoms

Targeted drugs

Targeted drugs are treatments that affect how some cells in your body work and may be used to treat secondary bone cancer. They can stop the activity of cells that break down bones (osteoclasts) so bones are strengthened, helping to prevent bone fractures and other secondary cancer-related bone problems.

These drugs may be given to you even if you currently don't have any symptoms to help prevent them developing. Treatment is by injection usually every four weeks. Some side effects may include:

- bone, joint, and/or muscle pain that is sometimes severe
- shortness of breath
- diarrhoea
- low blood phosphate levels
- excessive sweating

Biphosphonates

Where bone is being broken down faster than it is being replaced, your bones become thinner and weaker. The process releases the calcium from your bones into the blood, and high levels of calcium leads to a condition called *hypercalcaemia*.

Biphosphonates can help stop or slow down bone thinning, or *osteoporosis*, and are sometimes used as a treatment where cancer is damaging bones. They are a bone hardening treatment and can be used to treat hypercalcaemia.

Symptoms of hypercalcaemia include feeling thirsty, sick or drowsy, and being constipated. It is very important that you speak to your GP or out-of-hours doctors if you have these symptoms.

The bisphosphonate used to treat lung cancer bone metastasis is zoledronic acid (brand name Zometa®) and is given by drip into your bloodstream. You will be given this in hospital on a regular basis.

Some side effects of taking zoledronic acid include:

- fever and flu like symptoms
- bone and joint pain
- changes to your kidneys (you'll have regular blood tests to check how well your kidneys are working)
- tiredness and low energy levels
- feeling sick and being sick
- low levels of calcium in your blood (*hypocalcaemia*)
- changes in bowel movements such as constipation or diarrhoea
- irritation of the food pipe (*oesophagus*)

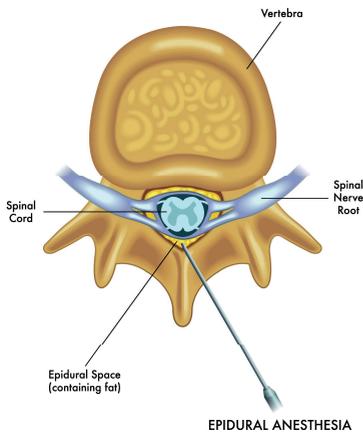
Steroids

Steroids can help reduce pressure and swelling caused as tumours grow, particularly if the cancer affects the bones in your spine. People getting treated with a steroid would typically get one called *dexamethasone*, and symptoms may generally improve within 24 to 72 hours.

As with many drugs, steroids may cause significant side effects, including:

- weight gain and increased appetite
- muscle weakness
- fluid retention (swollen hands, feet and ankles) and skin thinning
- unusual pattern of energy levels, perhaps causing sleep problems
- changes in mood and behaviour
- increased risk of infection
- a rise in blood sugar levels (especially if you are diabetic)

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



Surgery

Surgery may be used to treat secondary bone tumours where a bone has been weakened and is at risk of breaking.

Particularly where a bone is weight bearing, such as the thigh bone (*femur*), a surgeon may strengthen a weakened bone by putting a metal rod down the middle of the bone or fixing a metal plate or pins on the outside of the bone.

This would usually be done under a general anaesthetic, although for operation on hips or leg bones, a spinal injection (*epidural*) may be used.

Clinical trials

Clinical trials are an essential part of medical research. They are a way of finding out if new treatments are better than current best practice. Progress in medicine depends on people wanting to take part in trials so that their own situation may help generate new knowledge about the potential benefits and/or risks of newly developed drugs or treatment approaches.

People take part in clinical trials for different reasons. You may:

- hope that a new experimental treatment will be better than treatment you would otherwise be offered
- want to be part of “cutting edge” medicine
- hope that others may benefit from the knowledge gained from how the treatment works for you

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, related to the treatment you are having or not, are picked up and acted upon earlier than if you were not in a trial.

Clinical trials usually compare a new treatment with current best practice. To be able to make this comparison, trials recruit a group of people, some of whom receive the new treatment and the others receive the current best available treatment. People are randomly allocated to one group or the other, so you may not have any control over whether you receive the new treatment.

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, though people already getting the drug may continue to receive it for as long as it is effective.

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 for the trial and where it is taking place.



To check what clinical trials are available, visit:

- **UK Clinical Trials Gateway**

www.bepartofresearch.nihr.ac.uk

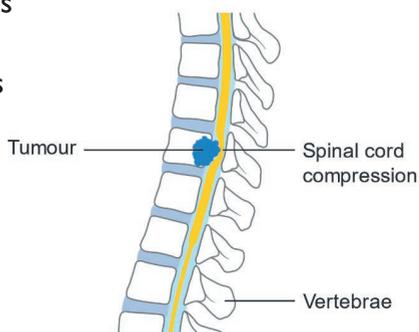
- **Cancer Research UK**

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

Metastatic spinal cord compression (MSCC)

The spinal cord is a long bundle of nerves that runs from the brain to the tail bone (coccyx). It is well protected by the bones of the back (vertebrae).

As it goes down the back, smaller nerves branch off and, depending on the level of the branch, these nerves can control, for example, your arms, legs, digestion, bowel and bladder function.



The vertebrae are common sites for lung cancer bone metastases. If a tumour does form here, it can grow and put pressure on the spinal cord and can cause pain, altered sensation, such as tingling in your legs, and weakness.

Symptoms of MSCC

The symptoms of having a tumour that has started to press on your spinal cord will vary depending on where it is. You may have pain before other symptoms develop. These symptoms may include:

- an ache in your neck or back, or in the area of your body relating to the nerves affected (perhaps spreading around the side of your body or down your arms or legs, or a band type pain around your chest or abdomen)
- nerve pain, sometimes describes as burning or shooting
- some change in sensation and strength in your arms and hands, or your legs (“heavy legs” or difficulty walking)
- not being able to empty your bladder
- loss of control of your bowel and your bladder

Your medical team will likely give you specific information about being aware of MSCC and watching for symptoms.

Metastatic spinal cord compression is a medical emergency. If you start to experience any of the above symptoms, get urgent advice. Speak to the hospital staff where you usually go for your cancer follow-up clinics or treatment, your GP or lung cancer nurse specialist, or call NHS 24 on 111 at any time of the day.

In an emergency, always call 999.

Describe your symptoms and explain that you are worried about metastatic spinal cord compression and need to be seen urgently.

Don't delay. Ring someone today, even if it is at the weekend or a holiday period.

Treating metastatic spinal cord compression

There are several treatment options for metastatic spinal cord compression, and your medical team will need to assess the extent of the condition before deciding on the best options for you.

Within 24 hours, you are likely to have a scan of your spine to confirm the diagnosis and see where the spine and nerves are affected, and to check for any other metastases outside your spine.

Sudden movements of the spine can make things worse and you will need to rest flat in bed until you have had your scan. If the scan shows that the tumour is making your spine unstable, you may need to stay on your back until you have had treatment to stabilise it.

Radiotherapy

The priority for treatment is to take pressure off the spinal cord and minimise any further damage. Radiotherapy uses high energy X-rays to shrink the tumour. The aim is to improve your symptoms and relieve pain.

If there are going to be any noticeable improvements after radiotherapy treatment, these can take two to four weeks to show up.

Depending on the part of the spine that is treated, there may be some side effects. These would show up about a week after your treatment. For example, if your treatment is around your neck area, you may develop a sore throat. Radiotherapy to your upper spine (chest area) may mean you have some temporary soreness when swallowing, and lower back treatment may cause you to feel sick or to be sick. This symptom can be reduced by taking anti-sickness tablets.

Medicines

You may also be given medicines called steroids to reduce pressure and swelling around the affected nerves in your back. This is likely to be dexamethasone. Painkillers will also help.

Other drugs used for treatment include bisphosphonates and targeted drugs (see page 20).

Surgery

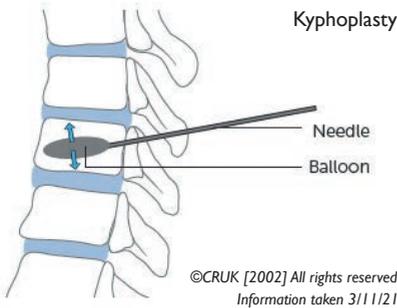
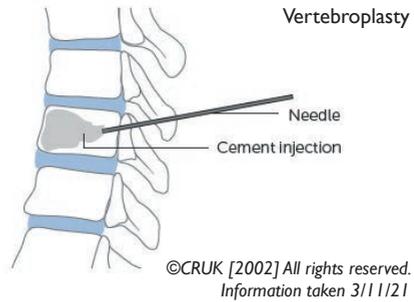
Surgery may be an option if you are well enough to undergo an operation. Any surgery would be to reduce any spinal cord compression and give stability to the spinal column.

You would have a general anaesthetic. A surgeon would try to remove the tumour and any bone that may be pressing on the spinal cord. Some people may have steel rods put into their spine to strengthen it.

Vertebroplasty and kyphoplasty

If one or more bones in your spine (*vertebrae*) are collapsing, or your pain is not well controlled with painkillers, you may have one of these procedures.

Vertebroplasty is where your doctor injects a special medical cement into the damaged bone area that is affecting your spine to try to recover the correct spacing for your spinal cord. Once hardened, it acts like an internal plaster cast.



The aim of *kyphoplasty* is the same, but the procedure is slightly different. A small balloon is inserted into the fractured bone and carefully inflated to correct the bone's shape. The balloon is then deflated and removed leaving a small cavity.

This cavity is then filled with bone cement which hardens and stabilises the fractured vertebrae.

A radiologist uses X-rays to help guide these procedures. Both may be done under a local or a general anaesthetic. The cement hardens quite quickly, but afterwards, you will need to lie on your front without moving, perhaps for several hours, until the cement is completely set.

What other support can I get?

Palliative care

Palliative care describes care, support and symptom management that is given to someone when a cure is not possible. This approach to care is not the same as end-of-life and may start as soon as you are diagnosed. You can get referred at any time to palliative care to get support with managing your symptoms.

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 specialist or GP about palliative care.



Other NHS support services

Some of the problems and symptoms associated with bone metastases don't get resolved when the tumour is treated. For example, you may continue to have pain or problems walking, and you may be trying to manage these along with other symptoms associated with lung cancer such as difficulties with breathing, speaking, eating 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 coordination 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 is 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.
- **Nutritionists and dietitians** – they assess, diagnose and treat dietary and nutritional problems, and help you make the right choices about what you eat.

If you are finding it hard to get around, do some 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.

Using hospice services

Hospice care is not just about end-of-life care. Every year, hospices also provide day services, respite care and support to around 200,000 people, including adults and children with life-limiting or terminal conditions, and their families and friends.

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 and provided for however long it is needed – days, weeks or even months. Not everyone has a hospice nearby, but hospice care may also be offered in the community or at home.

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, by visiting: www.hospiceuk.org

Information and networking

One of the ways many people find helpful in coping with lung cancer in general, and bone metastases in particular, is to ask questions and have a notebook or folder to keep things together. Answers to some questions can also lead to finding new questions to ask.

Your cancer doctors, lung cancer nurse specialist, GP and other healthcare professionals may all be able to help you understand more about your illness. You may be able to find out more information about your disease, ask about current or future treatment options and talk about how to take good care of yourself.

While searching the internet for more information can easily be overwhelming, not to mention terrifying, many people feel more in control of what is happening to them by being better informed. Make sure you are using recognised and reputable sites for your information.



You can find out more information here:

- www.roycastle.org
- www.cancerresearchuk.org
- www.macmillan.org.uk
- www.nhs.uk
- www.nhsinform.scot

Finding someone to talk through your problems with is also a great way to help you cope with what is happening to you. Talking about it with family or friends may work for you, though someone independent, such as a counsellor, may be a better option.

Being able to speak to other people living with cancer can be a good way of helping you through difficult times and boost your mood and confidence. You can find out from them ways to help you deal with your cancer and help with your motivation.



Your hospital may have a lung cancer support group, so ask your lung cancer nurse specialist.

Other groups are online, including Roy Castle Lung Cancer Foundation's own forum at:
www.healthunlocked.com/lungcancer



Some online groups are only open to people with cancer, and you can usually connect with someone else going through what you are going through and get support. Remember though, that some online groups are not moderated by healthcare professionals or other experts, meaning you may need to be wary of trusting some medical information presented there.

More information and support

We offer a range of support to people affected by lung cancer:

Roy Castle Lung Cancer Foundation Ask the nurse service

If you or someone you know needs support, we are here to help. Our Ask the nurse service is a nurse-led helpline and we are able to offer advice on:

- where to get help on side effects
- ways of managing how you, your family and friends are affected by lung cancer
- understanding treatment decisions/options
- any other issues around diagnosis and treatment

Call our experienced team of nurses free on: **0800 358 7200**, Monday to Thursday, 9.00am to 5.00pm, and Friday 9.00am to 4.00pm, or email: lungcancerhelp@roycastle.org

Lung cancer information days

Throughout the year, Roy Castle Lung Cancer Foundation organises information days, offering support and information to people affected by lung cancer.

Lung cancer professionals including oncologists, thoracic surgeons and lung cancer nurse specialists are among the experts who attend. You will have the opportunity to ask them questions as well as meet other people affected by lung cancer with whom you can share your experiences.

To find out more information and to reserve your place at one of our upcoming events, please call: **0333 323 7200** (option 2).

I have found sometimes that there is a burden to always appear 'fine' with those closest to me. Finding a couple of support groups to spend time with other people (either online or in person) who are also diagnosed with lung cancer has helped me a lot.

Nicola

Online support

There are many cancer-related website-based discussion forums. They provide an online community for people to ask questions, share knowledge and experiences, exchange ideas and support each other.

Other social networks also have groups where people in similar situations can connect and share information and experiences. For example, Facebook has groups specifically for people with EGFR and ALK positive non-small cell lung cancer.

Groups like these are often closed groups, meaning that membership is controlled, and usually restricted to people affected by the condition or situation covered by the group description.

They can also be international and you can connect to people all over the world with a vast range of experiences, many similar to yours. Be aware, though, that many may not be moderated (where posts and information are checked and screened) by healthcare professionals or experts.

Our online forum lets you share your experience through blog posts and questions with other people affected by lung cancer:

www.healthunlocked.com/lungcancer

Other things to think about

Having a serious illness can have a significant impact on your life.

It is all too easy to get on with the day-to-day things and leave more challenging issues to deal with “tomorrow”. Having a diagnosis of advanced lung cancer brings the reality of life and death into sharp relief.

It can change people’s perspective, and indeed some people decide that now is the time to ask some difficult questions, focus on what’s important to them, and make significant decisions.

It brings many previously-avoided subjects into view, one of which is about the quality of life you want during the time you have left as well as how much more time any treatments may give you.

Coming to terms with this reality is easier for some than for others. There are certainly lots of questions to ask, and you may realise there is so much to do and people to see over an uncertain length of time.

Doctors won’t be able to be specific about how long people have. While some people may be coming to terms with having only weeks or months to live, some people do confound the medics and live for much longer. As treatments are developing all the time, life expectancy is always changing too, so check that any information you read is up to date.

This section is about helping you to plan and be well organised. By doing so, your time and energy can be best spent being as well as you can be during your illness. It will also support you to be able to approach those close to you about difficult subjects.

Everyone deals with this situation differently. While some may simply press on and tackle their to do list without hesitation, others find just getting through each day as it comes as much as they can face. However you choose to go forward is right for you.

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 whose job it is to 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 DS1500 form. This form is from the Department for Work and Pensions and will make sure any benefits claims are dealt with quickly.

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. 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, and have limited savings or low income, Roy Castle Lung Cancer Foundation offers small grants of up to £150. You can find out more and apply here:

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

Macmillan Cancer Support and the Citizens Advice Bureau can provide good independent sources of advice. Macmillan Cancer Support also offer small one-off grants.

A number of law companies can offer help and advice, and some will offer a discounted service if you are supporting a favourite charity.

Looking after yourself and others

If you are worried about what happens if your health gets worse, it may be worth considering what you want and who best to involve in planning and understanding what is important to you.

These can be difficult things to think about and face, so get some support and consider these things when you feel able. It may be that you are ready to talk about some things before 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. You may also find it helps to write things down.

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 powers of attorney, where you can nominate the person you want to make decisions on your behalf and what decisions they can make, for example about your welfare, finances and property.



Power of attorney varies from country to country:

England and Wales: www.gov.uk/power-of-attorney

Scotland: www.publicguardian-scotland.gov.uk/power-of-attorney

Northern Ireland: www.nidirect.gov.uk/articles/managing-your-affairs-and-enduring-power-attorney

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. Getting help to think through what you need to help you in your caring role can reduce some of your fears and worries.

Looking ahead

Not everyone with bone metastases has symptoms, and that fact that you are affected may only have been discovered during other routine checks. For others, pain or bone fractures may have led to it being diagnosed.

Some people find their diagnosis of bone metastases more than enough to handle going forward. However, you may want to ask healthcare professionals involved in your care how your illness may progress and affect you more in the coming weeks and months.

Though perhaps a scary prospect, you may feel it is more important to get as much information as possible ahead of time so you can be more prepared, make decisions and plan.

We have suggested here some things you may want to think about. It isn't a comprehensive list of the ways that bone metastases and lung cancer may affect people over time, but it may help you ask questions and start useful conversations.

If you feel overwhelmed by the situation or are struggling to cope, speak to your lung cancer nurse specialist or GP.

Watching for symptoms and being prepared

You may currently have no symptoms specifically related to bone metastases, though you may have other symptoms related to your lung cancer. While a new symptom or pain may be unrelated, it is still important to pay attention to new or changing aches and pains.

Things can happen slowly and you may, for example, notice a difference in the range of activities you feel able to do.

For people with bone metastases, doctors talk about *skeletal related events* (SRE). These are complications of the condition relating to your bone structure and strength. They show up as the pain, pathological fracture, spinal cord compression and raised blood calcium described earlier in this booklet.

If you find out how your condition may change over the coming weeks, it gives you the chance to be better prepared.

Things that you may be able to do now without thinking may become more difficult and even put you at risk of harm. Walking unaided, using stairs in your house or outside, and being able to cook safely are all things that can be affected.

While it may seem overdramatic, particularly if you feel quite well now, thinking ahead realistically about potential difficulties can help you and those supporting you to manage better over time. For example, you may become less steady on your feet and be more prone to falls or start to struggle to prop yourself up in bed. Preparing in advance like this can make it less stressful if it does happen.

Your doctors and other healthcare professionals will not be able to predict if or when your circumstances will change, however they will be able to speak to you about some things you could find out about.

You may want to speak to physiotherapists, occupational therapists, dietitians, and other doctors and nurses in your cancer and palliative care teams.

Physical aids and adaptations

Having bone metastases means that you may have to take extra care to try to avoid trips and falls. You may also have to find new ways to do some activities to reduce the risk of putting too much stress on your affected bones.

Different aspects of your day-to-day life can be assessed by, for example, an occupational therapist, to identify possible risks and how these can be minimised while supporting you to continue to be as independent as possible.

When looking at how you may be affected, your healthcare team will likely ask you about your home, such as where your bedroom and bathroom are, any steps and stairs, and how easily you can get around with and without help, and using public transport or driving.

Depending on your circumstances, this help may include:

- equipment that can help you get around more safely, such as walking sticks or frames
- adaptations around your home, such as a stair lift, or changes in your bathroom, such as a walk-in shower
- supportive frames, splints or braces, (sometimes called *orthoses*) that you can wear to reduce pressure on affected bones

Support of friends and family

While it is important that you know as much as you can about your condition and treatment, it is also important that those close to you understand as much as they can. This means they can be more involved and be clearer about the things they can do to best help you.

Having lung cancer and bone metastases can affect every aspect of your life, and it can be all too easy to feel overwhelmed and isolated. If those close to you are unaware of your condition, your treatments and any plan to help you cope, they may feel helpless, even distressed that they don't know what to do for the best.

Many people are reluctant to ask for help so they don't appear weak or be a burden to others. However, if people see that you could do with some help, most will do whatever they can. You may not even need to ask.

This help may be driving you to a hospital appointment, preparing a tasty meal, or just enjoying a hot drink and a biscuit with you. Others may be able to help you about the house or help motivate you to do things.

Questions to ask your doctor or nurse

1. Why has my lung cancer spread to my bones?
2. Which bones are involved and is it likely to get worse?
3. What tests am I likely to have and what are they for?
4. What treatment options are there for me?
5. How will the bone metastases affect me?
6. Will I have more symptoms?
7. Is there anything that could stop me having treatment?
8. What options are available if I can't (or choose not to) have treatment?
9. Who will look after my care?
10. If I have treatment, what results can I expect?
11. Is there anything I can't do during treatment?
12. Can I go on holiday? Can I go abroad? What about travel insurance?
13. What other support is available?
14. What about clinical trial? Should I think about trying to get on one?
15. What can I do to help myself? Should I take supplements, such as calcium, vitamin D or fish oils?

Useful contacts

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/](http://www.lawsociety.org.uk/for-the-public/common-legal-issues/)

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

Published: November 2021 | Next review: November 2024

© Roy Castle Lung Cancer Foundation

Registered charity number England and Wales 1046854 - Scotland SC037596 - Isle of Man: 1277

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, including photocopying, recording or otherwise, without the prior permission of Roy Castle Lung Cancer Foundation.



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

Expect Better



[Roycastlelungcancer](https://www.facebook.com/Roycastlelungcancer)



[@Roy_Castle_Lung](https://twitter.com/Roy_Castle_Lung)