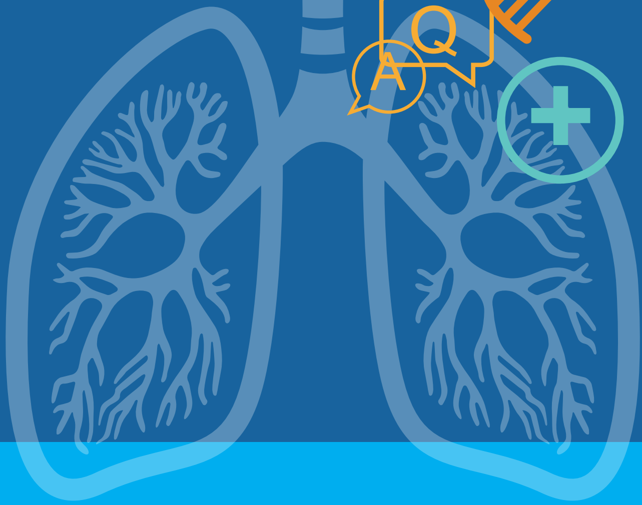
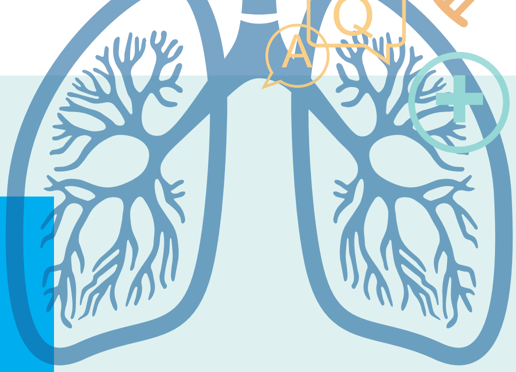


ALK POSITIVE UK

ALK+ NSCLC shared decision-making tool

Introduction

About this tool



After being diagnosed with anaplastic lymphoma kinase-positive (ALK+) non-small-cell lung cancer (NSCLC), you will probably have a lot of questions about how your life will change and what you can do to take control. It can be difficult to know where to start looking for answers, which is why Pfizer UK has partnered with the charity ALK+ UK to give you the information you really need.

Our research shows that people with lung cancer can sometimes feel like decisions about their care are made without their input.[1–3] There are a few reasons why this can happen: some people with lung cancer don't fully understand their medical needs, don't know how to prepare for appointments, or don't feel confident enough to express their opinions.

This shared decision-making tool has been developed to make sure you can take an active role in discussions about ALK+ NSCLC. This document is not intended to replace your healthcare team's expertise – instead, it should be used to help start conversations about your care.

We've split the document up into five modules so you can go straight to the information you're interested in.

When you've read this document, you can also find more information about ALK+ NSCLC on the ALK Positive UK charity website, where you can meet other people in your situation and find out how they've learned to live with cancer.

www.alkpositive.org.uk

Module 1 • Page 4

So you've just found out you're ALK+

This section will teach you the basic science behind ALK+ NSCLC and how the condition tends to develop after the first symptoms appear. Most people haven't heard of ALK+ NSCLC and tend to think lung cancer is only found in smokers, we hope this booklet will help you understand ALK+ a little better.

Module 2 • Page 8

Preparing for medical appointments

This section has practical advice for making the most of your consultations with your healthcare team. We know that time with doctors may feel very rushed, particularly at the start of your treatment when you're still trying to wrap your head around your situation. It's vital to go into those appointments ready to share your thoughts and feelings.

Another aspect of medical care for ALK+ NSCLC is regular scans and tests to track the growth of the cancer – waiting for the results can be daunting for some people. To help you manage, we've put together a short guide about the scans and tests you'll probably go through and what to do if you experience 'scan-xiety'.

Module 3 • Page 12

What is shared decision making?

Lots of people find it helpful to understand how they can take a more active role in their medical care. This is often called 'shared decision making'. This doesn't mean ignoring or overruling your healthcare team – it's about working together to create a treatment plan that you can stick to and being open and honest when you're struggling with side effects. To help you make decisions about treatment, we've put together a quick explanation of the main types of treatment that people with ALK+ NSCLC tend to get.

Module 4 • Page 16

Setting your priorities

Possibly the most important part of this document is our shared decision-making questionnaire. We'd recommend taking a look at this before each of your medical appointments so you can prioritise what you want to discuss.

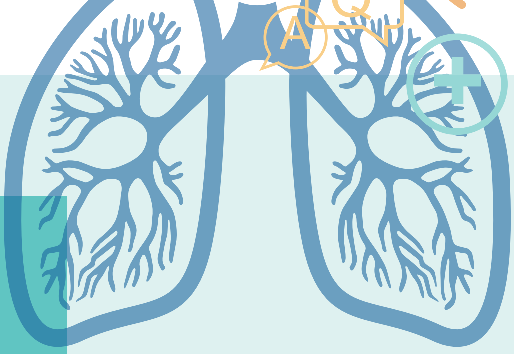
Module 5 • Page 20

Glossary

This section will lay out clear, concise definitions of the medical terminology you're likely to hear or read while learning about ALK+ NSCLC. Please refer back to our glossary any time you find something you're unfamiliar with.

Module 1

So you've just found out you're ALK+



What is ALK+ NSCLC?

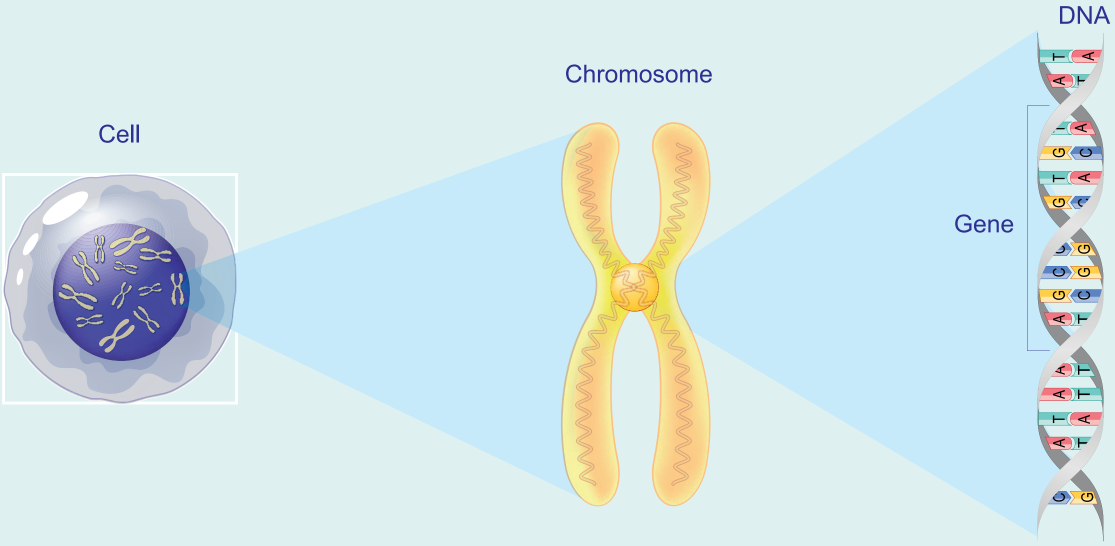
Cancer is caused by tiny changes to your DNA - the instructions that control the behaviour of all the cells in your body. DNA is found in the form of chromosomes, which contain the instructions for multiple bodily functions and characteristics.[4]

Each of these instructions are found within individual segments, called genes, that make up the chromosome. When cells multiply, errors can appear in the instructions that change their function – this is called a mutation.[4]

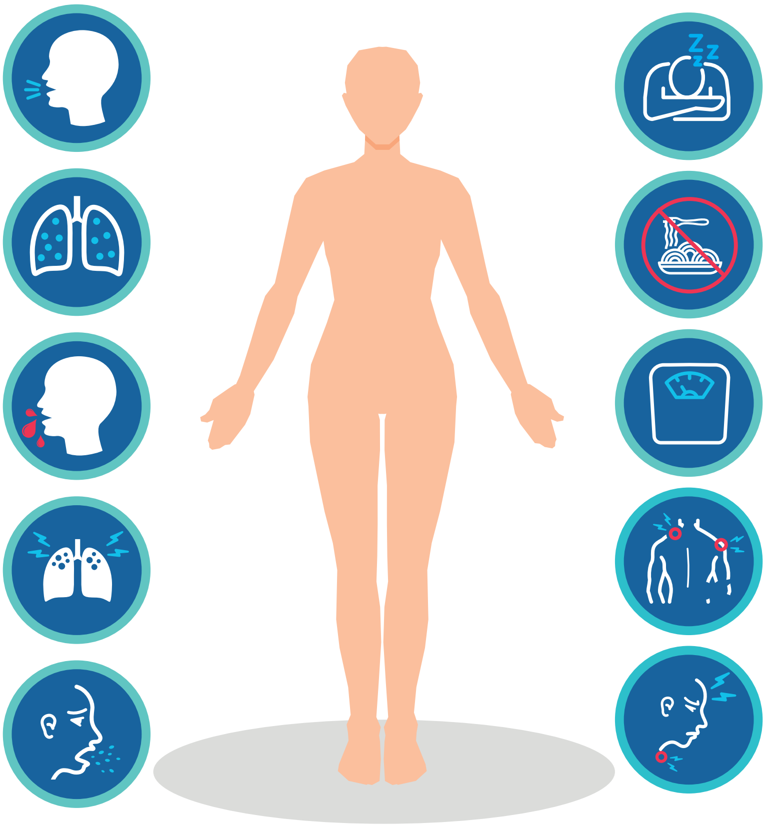
Most of the time, your immune system can find the cells carrying mutations and destroy them, but sometimes the mutations cause cells to multiply out of control. This leads to the growth of lumps called tumours that can spread to other parts of the body.[4]

Anaplastic lymphoma kinase-positive (ALK+) non-small-cell lung cancer (NSCLC) is a type of lung cancer caused by a mutation in the ALK gene.[5] Rather than being inherited (passed on from parents to their children), this mutation appears to happen randomly.

In this case, the ALK gene gets fused together with another gene (most commonly a gene named EML4) and that leads to the affected cells multiplying endlessly. Only around 4–5% of NSCLC is caused by the ALK mutation so it's rare enough that non-specialists might not think to look for it.[5]



Symptoms of ALK+ NSCLC[6]



- Persistent cough
- Repeated chest infections
- Coughing up blood
- Aches or pains when breathing/coughing
- Breathlessness
- Tiredness/ fatigue
- Loss of appetite
- Unexplained weight loss
- Pain in chest or shoulders
- Difficulty swallowing

Things to look out for

One key feature of ALK+ NSCLC is that it tends to spread (metastasise) to the brain.[5] Brain metastases (or just "brain mets") are a particular cause for concern, occurring in just under two out of three people with ALK+ NSCLC.[7] Brain mets can carry their own additional symptoms, such as headaches and problems with speech and vision.[8] Brain mets can change and, in some cases, grow quickly,[7] so it's important to have regular scans.

Other common sites for lung cancer metastasis include the bones, the other lung, the liver and the adrenal glands.[8]

People with liver mets could have a shorter life expectancy than other kinds of metastatic cancer, which some researchers suggest is because the liver normally has a key role in activating and breaking down anti-cancer drugs. You can learn more about metastatic cancer on the Macmillan Cancer Relief and Cancer Research UK websites.[9,10]

Blood clots can develop in your veins, most commonly in the veins in the legs. This is called a deep vein thrombosis (DVT). This can lead to pain, tenderness and swelling in patients' legs. If they are left untreated, the blood clot can embolise (or spread) to the lungs. This is called a pulmonary embolism (or "PE" for short). A PE can cause shortness of breath and chest pain and it is essential to seek medical advice as it is a potentially life threatening condition.[11]

Living with ALK+ NSCLC

Any diagnosis of cancer will mean big changes to your life, but ALK+ NSCLC can be particularly tough to manage. Many people only start to show symptoms when the cancer has already started to spread, meaning it may be too late for a definitive cure by the time they get diagnosed.[12,13]

It's okay to feel shocked, upset or even angry about that news. You should allow yourself the opportunity to work through your emotions. You should ask your healthcare team if it is possible to speak to a counsellor. A trained counsellor can help you to talk through your emotions and thoughts about your diagnosis confidentially and help you to come up with ways to manage these feelings.

A key source of worry for many people with cancer is how to pass the news on to their loved ones, particularly children. There's no easy answer here. Just try to be honest about your situation and how it makes you feel. Your family may also benefit from getting counselling if they're struggling to adapt to the diagnosis and the impact it may have on their day-to-day life. For example, the Ruth Strauss Foundation offers pre-bereavement counselling for children who may soon experience a loss in the family.[14]

From recently published data, the average life expectancy for someone diagnosed with metastatic ALK+ NSCLC is around 7 years.[15] That statistic can bring up mixed emotions, but keep in mind that that number is just an average and doesn't reflect the individual circumstances of every person included. It's also worth remembering that research into new therapies is ongoing, and the current standard of care for ALK+ NSCLC may evolve over the course of your treatment.

Life expectancy is a challenging and worrying concept for many people, but the majority are still able to work, travel and enjoy their hobbies. If there is any change in your health, you should seek advice from your oncologist about how to best manage this situation.

ALK+ NSCLC myth busters

There is a lot of misunderstanding about lung cancer, but it's important to know fact from fiction. Here are some myths busted:

Only smokers get lung cancer

Smoking is linked to increased risk of at least 15 different types of cancer, particularly lung cancer,[16] but 7 out of 10 people with ALK+ NSCLC have never smoked.[17]

Only older people get lung cancer

Most cases of lung cancer appear in people aged between 85 and 89 years,[18] but the average age of diagnosis with ALK+ NSCLC is 55 years old.[17]

Once you get brain mets you can never drive again

Your driving license will be suspended if you are diagnosed with brain mets BUT you should be able to get your license back if you receive effective treatment and don't show any signs of getting worse for 1 year.[19] You can find more about the specifics of driving restrictions on the ALK Positive UK website.

What do people with ALK+ say about diagnosis?

My lung cancer nurse had done some research and found online ALK Positive UK, a charity for people in my situation and said 'try it.' And it has been lifesaving in many ways. They have given me so much information about my condition that it has been so helpful.

To people who are newly diagnosed with ALK+, I would say empower yourself. Learn as much as you can about the disease, about the treatment, about centres of excellence...Get a second opinion. You can, you're allowed! Insist on brain MRIs. The risk for brain mets is there. Advocate for yourself. Empower yourself with knowledge. And live your life. Live your life as well as you can by using the tools that are out there to help you.

Lynne

When I was first diagnosed I sought and got psychological help - found that extremely useful. And I would urge anyone who's going through a similar diagnosis to seek professional help.

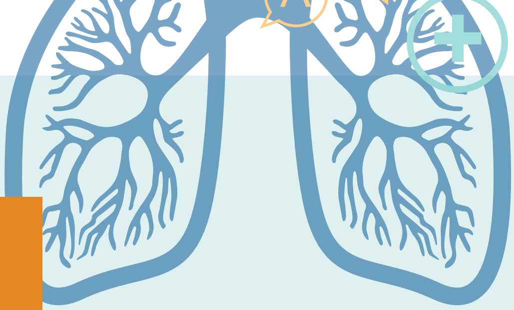
When I was first diagnosed with ALK+ I wish I'd known just how normal a life you could live with it.

We had to explain to my children what cancer was at a basic level and we took the decision early on to be upfront with them about exactly what my diagnosis was and what it meant.

Andy

Module 2

Preparing for medical appointments



Planning for your first oncology appointment

It's normal to get a little anxious before going to see an oncologist for the first time – or even after months of regular treatment. We've put together some advice on making the most of the opportunities you have to speak with them.

Before

- **Be prepared** - you want your healthcare team to understand any issues you're experiencing, and how your ALK+ NSCLC is affecting all aspects of your day-to-day life. Write down your concerns as clearly as you can. It may be helpful to make a list of occasions when symptoms such as fatigue have interfered with your daily routine, either at home, work or on social occasions.

- It might be helpful to score your concerns from 1 to 5, for example, a score of 1 being less worrisome and a score of 5 being really serious, or use a highlighter for the most important items. For example, if worries about your diagnosis are having a 5/5 impact on your personal relationships, such as with a partner or children, you should definitely tell your doctor.

- Make sure you have completed the questionnaire in Module 4. You can use it as a starting point for your discussions with your doctor. The questionnaire might also prompt you to ask your own questions.

- Be sure you are aware of the logistics for the day: where to go and who you should be seeing. This will minimise the stress you experience when you are seeing your healthcare team, and it will help you to be as a relaxed as possible before going to your appointment.

- If you need help organising transport to and from the appointment, consider reaching out to your loved ones, your healthcare team, or an organisation like Macmillan Cancer Support that can arrange something for you.

During

- It might be helpful to take a friend or family member with you to medical appointments for support. They might also be able to offer a different perspective on how ALK+ NSCLC is affecting your life. If you are taking someone, you should check with your healthcare team first.

- At the same time, you also have the right to speak to your healthcare team alone. If you're concerned that your loved ones would struggle to take part in difficult conversations, you may choose to ask them not to come with you.

- Take notes - this will help you to not only remember what was said, but to refer back to if you have the need for a future appointment. If you're having a virtual appointment, ask your healthcare team if they mind you recording what is said.
- Ask questions! If something isn't clear, ask your doctor, nurse or pharmacist to explain. You can simply say 'I'm sorry, would you mind explaining that again?' or 'I am still not fully clear on what this means.' No question is too big or too small.

After

- Next steps - it is really helpful to confirm next steps with your doctor before you appointment ends. That way you can be sure you haven't missed anything, and you know what to expect next.
- Make note of any important dates coming up. This could be when you're going to start a new medication, the time of your next appointment, or when you're going to have a scan.
- Keep a diary including: date and time of medical appointments; the start and end date of medications; any side effects or health issues you experience; and how you are feeling day to day. There may be so much to remember that it's good to have everything in one place to refer back to.[1]

Planning for your first scan

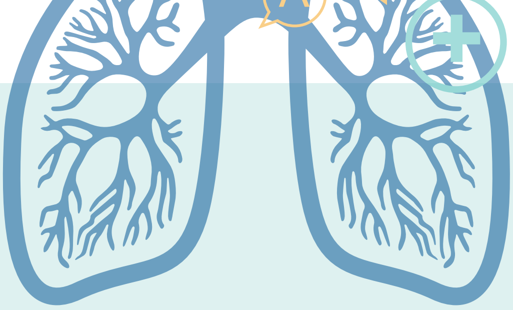
What scans might be needed for ALK+ NSCLC

Most medical scans are carried out by technical specialists called radiographers. The scans are interpreted by doctors called radiologists. Someone should talk you through the process of the specific type of scan beforehand, but here's some information to help you go in prepared.

Computerised tomography (CT) scans:[20]

CT scans use X-ray radiation. A CT scan takes flat X-ray images from lots of different angles and then uses a computer program to layer them together to form a very detailed image.

Before the scan, you may be given an injection of a dye (also called a contrast medium) that makes the results of the scan clearer. The dye will come through a small tube called a cannula that is inserted into your arm. You may feel a strange sensation during the injection, but this is normal. You'll be asked to lie back on a flat bed that carries you into the CT machine. The bed will move back and forth through the CT machine while it takes X-ray images of different parts of your body.



You will be asked to stay still for the scan, which will probably take about 10 minutes.[21] If you become uncomfortable, you can speak to the radiographer through an intercom and ask to adjust your position.

The test results can take a couple of weeks to be analysed and given to your oncologist, so don't worry if you don't hear anything straight away.

Magnetic resonance imaging (MRI) scans:[23]

An MRI scan uses magnetism to build a 3D map of the inside of your body. They are very good at showing soft tissues (like the lungs and brain) that contain a lot of water. This means they are excellent at finding and monitoring cancerous tumours.

You'll be asked to lie back on a couch that slides into the MRI machine, which is shaped like a doughnut. The machine is loud and the space is quite tight. This may, for some, be uncomfortable – talk to the radiographer if you feel anxious. You should be given headphones so you can listen to music and you will be able speak to the people outside the machine at all times.

Your oncologist should get the radiologist's analysis within a couple of weeks.

Positron emission tomography (PET) scans:[24]

Rather than X-rays or magnetism, PET scans create 3D images using a radioactive chemical that is injected through a cannula and travels to cancer cells in your body. PET scans are used less often than CT or MRI, but can be useful for monitoring changes to a tumour that the other scans have already identified.

To make sure the radioactive chemical shows up properly in the scan, you will be asked to not eat for up to 6 hours beforehand. You can still drink unflavoured water.

After the dye is injected, you will need to wait about an hour for it to travel to the cancer cells. During this time, you should try to rest and limit your movement. The radioactive chemical is a type of sugar, which could accidentally be used up by exercise.

The scan itself takes place in a doughnut-shaped machine. You will be asked to lie on a flat bed that moves through the scanner. The scan can take around 45 minutes, which can get a little uncomfortable. There will be an intercom the lets you tell the radiographer if you need to change position.

Electrocardiogram (ECG):[22]

An ECG measures the electrical signals that pass through your heart with every beat. You might be asked to have an ECG if you're getting ready for surgery, if you're taking chemotherapy drugs that may damage your heart, or if you become unwell.

The process is simple, and doesn't carry any known health risks. A doctor or nurse will ask you to lie flat on a couch and remove some of the clothes on the top half of your body, then place several sticky pads on different points on your chest, wrists and ankles. These are then connected to the ECG machine with wires. The test only takes around 5 minutes. You'll be asked to stay still while the machine works, but you don't need to hold your breath. You might be given the results immediately, or your healthcare team may want to double check with a heart specialist first.

Planning for your first blood test

People with ALK+ NSCLC also need blood tests to make sure their treatment isn't causing harmful side effects.

What blood tests might be needed for ALK+ NSCLC?

Full blood count:[25]

Your blood contains several different kinds of cells, including red blood cells that carry oxygen around your body, white blood cells that fight cancers and infections, and platelets that help your blood to clot if you get a cut. A full blood count measures the different levels of these blood cells in circulation.

Different types of white blood cell are specialised to go after different targets. Neutrophils are a type of white blood cell that fight bacterial infections, but their number can be reduced by some medications for treating cancer. Your healthcare team will monitor the full blood count results closely to make sure your immune system stays strong.

Kidney function tests:[26]

Some medications for treating ALK+ NSCLC can cause kidney problems. Your healthcare team will monitor your kidney function using a few key tests. Creatinine is a substance that gets produced from the normal activity of muscles and gets filtered out of your blood into urine. If you have higher than normal creatinine levels in your blood, it could be an early sign of kidney damage. Likewise, doctors may test your blood for levels of urea, a chemical made when you digest protein.

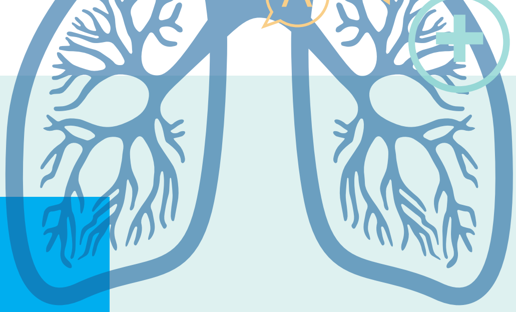
Liver function tests:[27]

One place that ALK+ NSCLC may spread to is your liver. Your liver has a lot of important jobs, one of which is breaking down medications and any waste products from normal bodily functions, so it's important for your healthcare team to make sure it's working properly, and they do this by testing the liver function.

Your doctor should explain the results of any tests you have, but please ask any questions you might have.

Module 3

What is shared decision making?



The key principles of shared decision making

Shared decision making is a philosophy whereby patients work with doctors to make informed choices on their treatment and care. To get the best possible care for you, it's important that your doctors and healthcare team provide you with trustworthy medical information, but it's also important that you are open and honest about your worries, thoughts and any questions you may have. Your oncologist is an expert in cancer, but you're the expert in your life and your needs.[28]

As an example, if your current treatment often leaves you feeling sleepy or irritable, you might be worried about not enjoying an upcoming event, such as a family celebration. If you just asked to change your medication out of nowhere, your doctor might be confused and suggest keeping your prescription the same. But if you are able to explain why you want to make a change, you may be able to reach a compromise such as a temporary (or even permanent) reduction in your dose.

Doctors don't always define goals for your treatment in the same way as you might, so it's helpful to try and understand each other's perspective.

Cancer specialists don't tend to use the word "cure" and that can be upsetting at first as it may sound like they're giving up. Instead, they might talk about control, which means stopping the cancer growing and spreading to other parts of the body. When you meet with your oncologist, or another member of the team, it's good to set out what you would like to achieve and find out how your goals align with those of your doctor.

There may come a point where your healthcare team's focus becomes helping you stay free from pain and discomfort, rather than actively treating the cancer. This is known as palliative care and is something they should take time to discuss with you before any decisions are made.

If you feel a member of your healthcare team isn't committed to making shared decisions with you, or that they're ignoring a key piece of information that could affect your treatment, you are entitled to ask for a new specialist who can offer a second opinion. This may not always get you the answer you want, but it's worth considering if you're not satisfied with your care.

Understanding your treatment options

Targeted ALK inhibitors[29]

These medications are specifically designed to target the processes that the mutated ALK gene has disrupted. Clinical trials have shown that they can delay the progression of ALK+ NSCLC significantly more than chemotherapy on its own. ALK inhibitors also carry some side effects, such as fatigue, nausea, vomiting, constipation, diarrhoea and vision changes. More serious side effects include inflammation of the lungs, liver or nerve damage, and heart rhythm problems.[30]

The information presented here isn't intended to replace your healthcare team's advice. If you're unsure how a decision about your treatment was made, your team should be able to answer your questions in your next appointment.

Chemotherapy[31]

Chemotherapy (sometimes just called "chemo") works by using drugs that kill cells while they are in the process of multiplying. Since that's how tumours grow, chemo can be an effective treatment for cancer.

Unfortunately, chemo also affects other parts of the body, such as your hair, skin, nails, gut and immune system. Side effects from chemo can be very unpleasant, but your healthcare team should be able to support you if you let them know about any side effects you may experience.

Radiotherapy[32]

Radiotherapy uses targeted radiation, often high-energy X-rays, to kill cancer cells. The length of treatment can vary, but a typical course would be 5 days a week for 4–7 weeks. Your healthcare team will give you more detail if this is relevant for you.

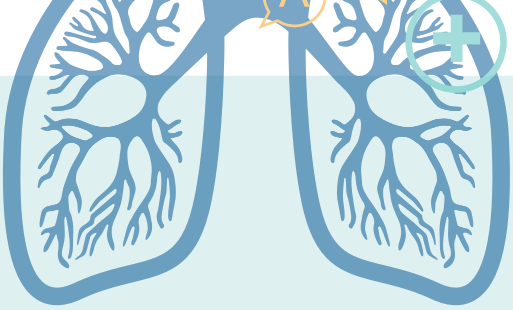
Radiotherapy is generally used in combination with other treatments:

- After surgery to kill any remaining traces of cancer
- After chemotherapy to boost effectiveness
- Alongside chemotherapy to boost effectiveness
- Can be used to help reduce symptoms associated with cancer e.g. pain from bone mets.

Radiotherapy does carry some side effects, like fatigue, sore throat and hair loss, but these should improve a couple of weeks after the end of treatment.

More long-term effects, like difficulty swallowing and a persistent cough, are more rare and may not appear for some time after radiotherapy has finished.

What is shared decision making?



Surgery[33]

The types of surgery that are possible for each person will depend on the kind of lung cancer they have, and how it has grown. If a tumour is too close to important structures like the heart or major blood vessels, surgery may be too risky. The lungs are divided into lobes: two in the left lung, three in the right lung. Surgery may involve removal of one or more lobes, or sometimes a whole lung.

If you are a candidate for surgery, your healthcare team will run a series of tests to help predict your lung function after the surgery.

After surgery you will need some time to recover, so make sure you have support from friends, family or a local volunteer to help you with essentials.

Managing side effects[30,34]

Going through treatment for cancer can be difficult. But it's important to remember that you aren't going through it alone. Don't forget to speak up if you're experiencing any side effects from treatment so that your healthcare team can suggest options for managing them.

You may find that side effects from new medications improve as you get used to the routine, but that isn't guaranteed. Speaking up about side effects doesn't make you a "difficult patient". It may be possible to reduce the dose of a particular medication, or switch to a different one entirely if you're struggling. There are also specific treatments that can be prescribed to help with certain side effects, as well as other techniques for managing side effects that your healthcare team will be able to advise you on.

What do people with ALK+ NSCLC say about treatment?

> *With the treatments available now, you're able to live a normal life for the time that the treatments work.*

Andy

Side effects

- Hair loss
- Dry skin
- Brittle nails
- More bruising or bleeding
- Increased risk of blood clots
- Changes to skin and nails
- Infections
- Loss of libido
- Loss of fertility
- Breathlessness
- Problems with memory and concentration (“chemo brain”)
- Anaemia
- Problems with hearing
- Emotional problems
- Trouble sleeping
- Loss of appetite
- Sore mouth
- Fatigue and tiredness
- Changes in vision
- Diarrhoea and constipation
- Nausea and vomiting
- Inflammation of lungs
- Liver damage
- Kidney damage
- Nerve damage
- Heart problems

This list doesn’t include every possible side effect of treatment. You’re the best judge of what feels right for you - if something isn’t right, make sure you let your healthcare team know.

Most side effects of treatment should hopefully go away once you stop taking the medication that causes them, but if you continue feeling unwell you should let your healthcare team know about that as well.

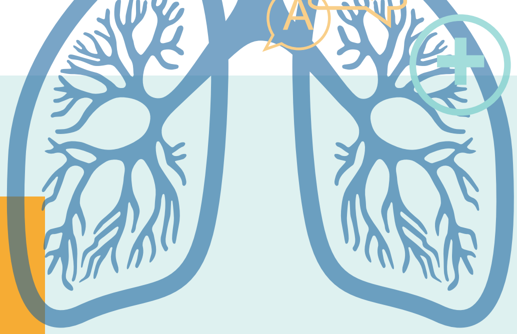
Lynne

> *For family I think the wonderful thing about the targeted treatments is that to look at me you would never know that I have cancer.*

> *Treatments are good. You can live your life.’ I have side effects - brain fog, fatigue, various things we don’t want to talk about like constipation, but it’s there - but I’m living my life, and I’m going on holiday, I’m seeing people, I’m going out for meals...I’m still here. And people need to know that it’s not the end of the world. There are treatments. You can live with ALK+ non-small cell lung cancer.*

Module 4

Setting your priorities?



This module has been developed to help you get ready for future medical appointments by giving you an opportunity to think about your own priorities. If you're using a printed version of the tool, you might want to write your answers on a separate piece of paper so you can reuse this questionnaire. If you are using a version you've downloaded, you can just save a new copy after you fill your answers in. If you keep copies of your answers, you and your healthcare team will be able to see how your health changes over time.

Part 1: Thinking about the last week...

1. Rate your general health status, with 1 being the worst and 10 being the best. ☐

2. Rate your mental health status, with 1 being the worst and 10 being the best. ☐

3. Have you experienced any worsening of symptoms of ALK+ NSCLC, such as cough, breathlessness or fatigue?

Alternatively, have you noticed that any of your symptoms improved?

4. Have you been experiencing any of the following symptoms since starting medication?

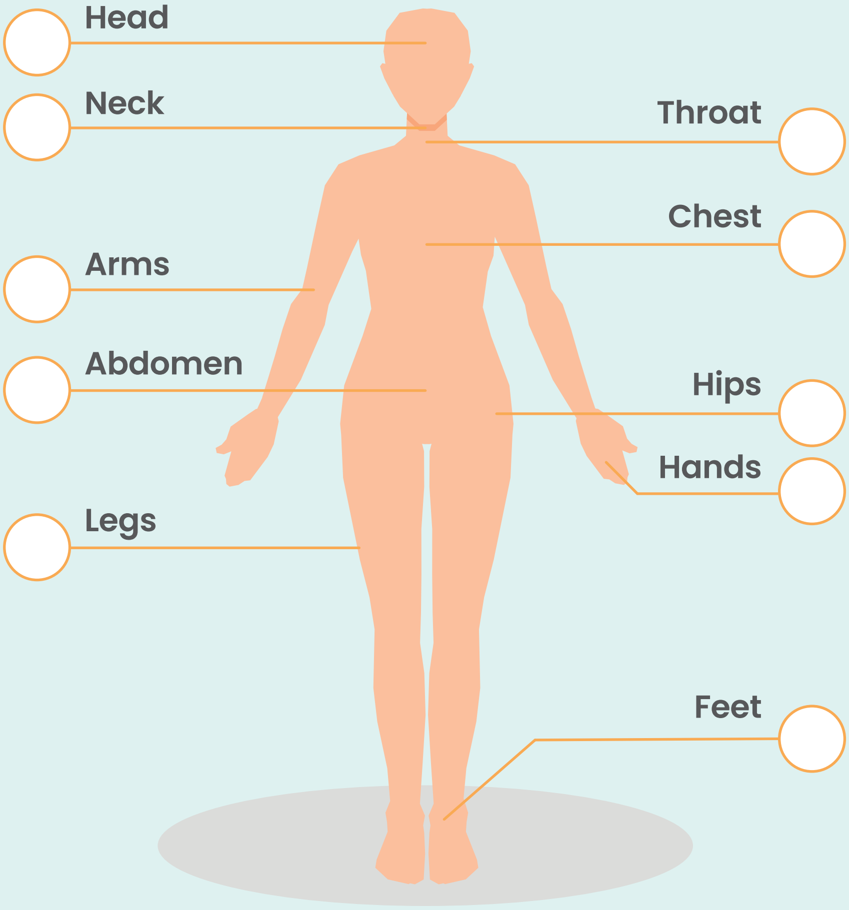
☐ Hair loss
☐ Dry skin
☐ Itchy skin
☐ Brittle nails
☐ More bruising or bleeding
☐ Changes to skin and nails
☐ Infections
☐ Change in sex drive
☐ Breathlessness
☐ Problems with memory and concentration
☐ Problems with hearing
☐ Mood swings
☐ Depression
☐ Trouble sleeping
☐ Loss of appetite
☐ Sore mouth
☐ Fatigue and tiredness
☐ Changes in vision
☐ Changes to chest pain
☐ Diarrhoea and constipation
☐ Nausea and vomiting
☐ More frequent need to pee
☐ More urgent need to pee
☐ Wheezing
☐ Numbness
☐ Pins and needles
☐ Muscle weakness

5. Have you experienced any other symptoms since taking your medication?

6. Have you had any significant concerns or worries about your health, your symptoms or your medication?

Setting your priorities?

7. If you've experienced any pain, please mark the places on the body that is has come from.



Other

Part 2: Thinking about the future...

1. Are there any important events coming up that your healthcare team should know about?

2. Do you have any questions about cancer progression, e.g. possibility of metastasis?

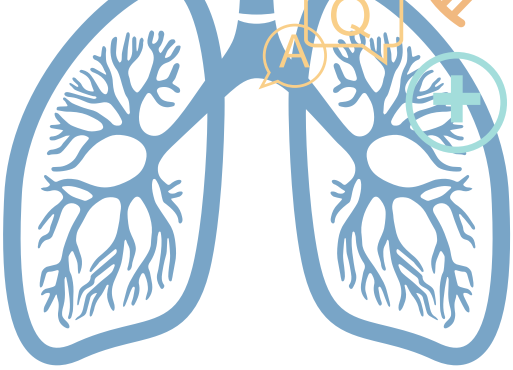
3. Do you have any questions about your future treatment, e.g. changes to medications?

4. Do you have any questions about future scans, e.g. when to expect the next MRI?

5. Do you have any questions about accessing practical support, e.g. financial advice?

6. Do you have any questions about accessing emotional support, e.g. counselling?

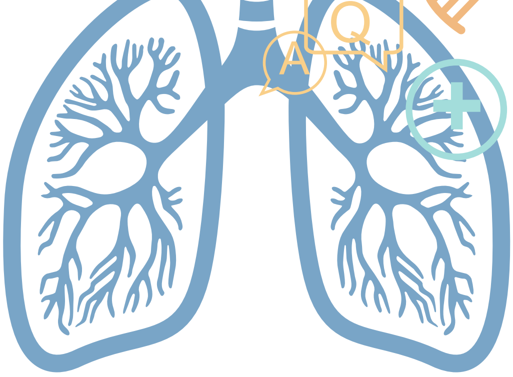
Glossary[35]



ALK inhibitor	A substance that blocks the activity of a protein called anaplastic lymphoma kinase (ALK), which helps control cell growth. Blocking this protein may help keep cancer cells from growing and spreading. Some ALK inhibitors are used to treat cancer. They are a type of targeted therapy.
Anaplastic lymphoma kinase (ALK)	A gene that makes a protein that is involved in cell growth. Mutated (changed) forms of the ALK gene and protein have been found in some types of cancer, including neuroblastoma, non-small cell lung cancer, and anaplastic large cell lymphoma. These changes may increase the growth of cancer cells. Checking for changes in the ALK gene in tumour tissue may help to plan cancer treatment.
Biopsy	The removal of cells or tissues for examination by a pathologist. The pathologist may study the tissue under a microscope or perform other tests on the cells or tissue.
Cancer Clinical Nurse Specialist or Cancer Specialist Nurse	A nurse who has additional education and training in how to diagnose and treat disease. In cancer care, a nurse practitioner may manage the primary care of patients and their families. A nurse specialising in the treatment of cancer patients. Usually work alongside oncologists and may be your main point of contact for treatment.
Cancer stage	The extent of a cancer in the body. Staging is usually based on the size of the tumour, whether lymph nodes contain cancer, and whether the cancer has spread from the original site to other parts of the body.
Carcinogen	Any substance that causes cancer.
Central nervous system(CNS)	The brain and spinal cord.
Computerised tomography (CT)scan	A procedure that uses a computer linked to an X-ray machine to make a series of detailed pictures of areas inside the body. The pictures are taken from different angles and are used to create three-dimensional (3-D) views of tissues and organs.
Counsellor	A specialist who talks to patients and their families about emotional and personal matters and can help them make decisions. Also called a mental health counsellor.
DNA	The molecules inside cells that carry genetic information and pass it from one generation to the next. Also called deoxyribonucleic acid.

Dose	The amount of medicine taken, or radiation given, at one time.
Enzyme	A protein that speeds up chemical reactions in the body.
Fatigue	A condition marked by extreme tiredness and inability to function due to lack of energy. Fatigue may be short term or long term.
Gene	The functional and physical unit of heredity passed from parent to offspring. Genes are pieces of DNA, and most genes contain the information for making a specific protein.
Magnetic resonance imaging (MRI)	A procedure in which radio waves and a powerful magnet linked to a computer are used to create detailed pictures of areas inside the body. These pictures can show the difference between normal and diseased tissue.
Metastasis	The spread of cancer cells from the place where they first formed to another part of the body. In metastasis, cancer cells break away from the original (primary) tumour, travel through the blood or lymph system, and form a new tumour in other organs or tissues of the body. The new, metastatic tumour is the same type of cancer as the primary tumour.
Multidisciplinary team (MDT)	A team that includes a number of doctors and other health care professionals who are experts in different specialties (disciplines). In cancer treatment, the primary disciplines are medical oncology (treatment with drugs), surgical oncology (treatment with surgery), and radiation oncology (treatment with radiation). The MDT can also invite other specialties to support you, including radiologists who interpret your scans, pharmacists who give out your medications, and neurologists who monitor changes in your nerves.
Mutation	Any change in the DNA sequence of a cell. Mutations may be caused by mistakes during cell division, or they may be caused by exposure to DNA-damaging agents in the environment. Mutations can be harmful, beneficial, or have no effect. If they occur in cells that make eggs or sperm, they can be inherited; if mutations occur in other types of cells, they are not inherited. Certain mutations may lead to cancer or other diseases.
Non-small-cell lung cancer (NSCLC)	A group of lung cancers named for the kinds of cells found in the cancer and how the cells look under a microscope. NSCLC is the most common of the two main types of lung cancer (NSCLC and small cell lung cancer). The three main sub-types of NSCLC are adenocarcinoma (most common), squamous cell carcinoma, and large cell carcinoma.

Glossary[35]



Oncogene	A gene that is a mutated (changed) form of a gene involved in normal cell growth. Oncogenes may cause the growth of cancer cells. Mutations in genes that become oncogenes can be inherited or caused by being exposed to substances in the environment that cause cancer.
Oncologist	A doctor who has special training in diagnosing and treating cancer. Some oncologists specialise in a particular type of cancer treatment. For example, a radiation oncologist specialises in treating cancer with radiation.
Progression	In medicine, the course of a disease, such as cancer, as it becomes worse or spreads in the body.
Protein	A molecule made up of amino acids. Proteins are needed for the body to function properly. They are the basis of body structures, such as skin and hair, and of other substances, such as enzymes, cytokines, and antibodies.
Remission	A decrease/disappearance of signs and symptoms of cancer. In partial remission, some, but not all, signs and symptoms of cancer have disappeared. In complete remission, all signs and symptoms of cancer have disappeared, although cancer still may be in the body.
Translocation	A genetic change in which a piece of one chromosome breaks off and attaches to another chromosome. Sometimes pieces from two different chromosomes will trade places with each other. Translocations may lead to medical problems such as leukaemia, breast cancer, schizophrenia, muscular dystrophy, and Down syndrome.

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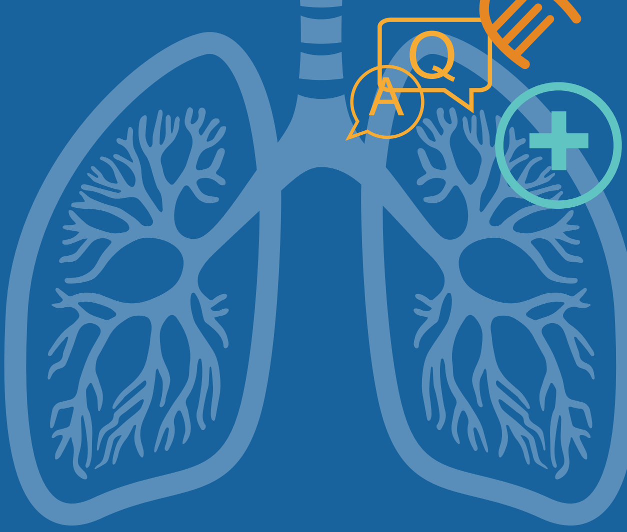

Reporting of side effects

If you get any side effects, talk to your doctor, pharmacist or nurse. This includes any possible side effects not listed in the package leaflet that accompanies your medication. You can also report side effects directly via the Yellow Card Scheme at https://yellowcard.mhra.gov.uk

By reporting side effects, you can help provide more information the safety of your medicine.

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