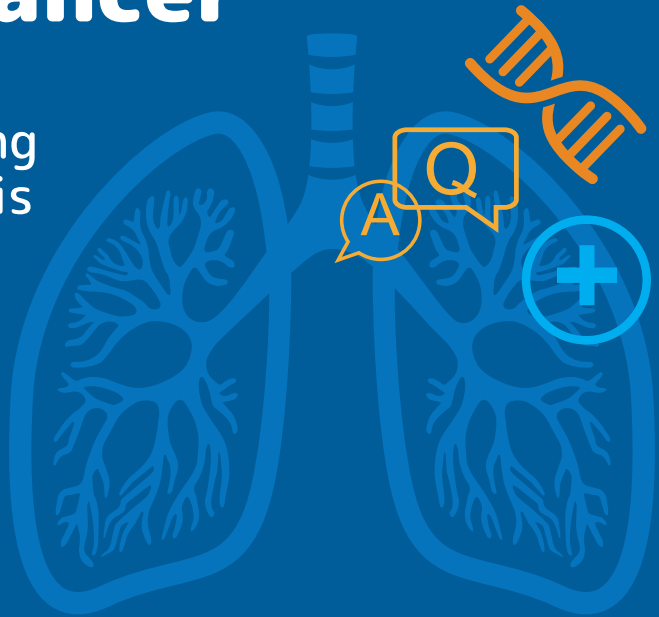




# Living with ALK Positive Lung Cancer

Understanding  
your diagnosis



This booklet is for anyone diagnosed with ALK positive lung cancer, their family and friends. We hope it gives you an understanding of what ALK positive lung cancer is, treatment options available and how to get support if you want or need it.

[www.alkpositive.org.uk](http://www.alkpositive.org.uk)

Prepared in collaboration with  
LUCÉ and Takeda EUCAN

# Lung cancer can affect anyone: an introduction to ALK+ lung cancer

Lung cancer is a complex disease that can have various causes. You are reading this brochure because you or someone you care for have been diagnosed with ALK+ lung cancer.

## Your ALK+ lung cancer diagnosis

Your initial lung cancer diagnosis will have been based on various tests, including imaging of your chest (e.g. x ray or CT scan) and other parts of your body.<sup>1</sup> After that, a small sample of tissue was taken from your lung in a process called a biopsy\*, to find out:<sup>2</sup>

- what your tumour looks like under the microscope
- whether your cancer is associated with any genetic changes (such as changes to the anaplastic lymphoma kinase [ALK],\* Epidermal Growth Factor Receptor [EGFR]\* or other receptor tyrosine kinase genes such as ROS1\*)

This testing confirmed that you have ALK+ lung cancer.

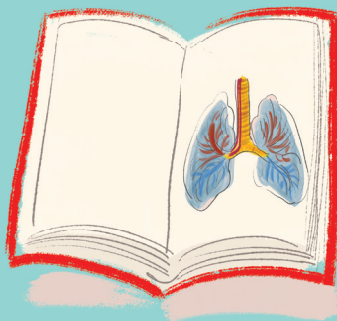
Most people with lung cancer have non-small cell lung cancer (NSCLC).<sup>3</sup> A small percentage of these people<sup>4</sup> – like you – test positive for ALK+ lung cancer. This means your cancer is caused by a change in the ALK gene.<sup>4</sup>

People diagnosed with ALK+ lung cancer are more likely to be:<sup>5</sup>

- Younger than 50 when diagnosed
- Non-smokers

People diagnosed with ALK+ lung cancer may have different needs and concerns to people with other kinds of lung cancer.

Importantly, there are also specific medicines available to treat ALK+ lung cancer.<sup>6</sup>



**This booklet provides information for people living with ALK+ lung cancer and their carers. You may wish to read the whole booklet or choose sections that you feel are most relevant to you.**

# The ALK gene (or ‘anaplastic lymphoma kinase’) and ALK+ lung cancer

Genetic changes related to lung cancer are usually acquired during a person’s lifetime – this is the case for people with ALK+ lung cancer.

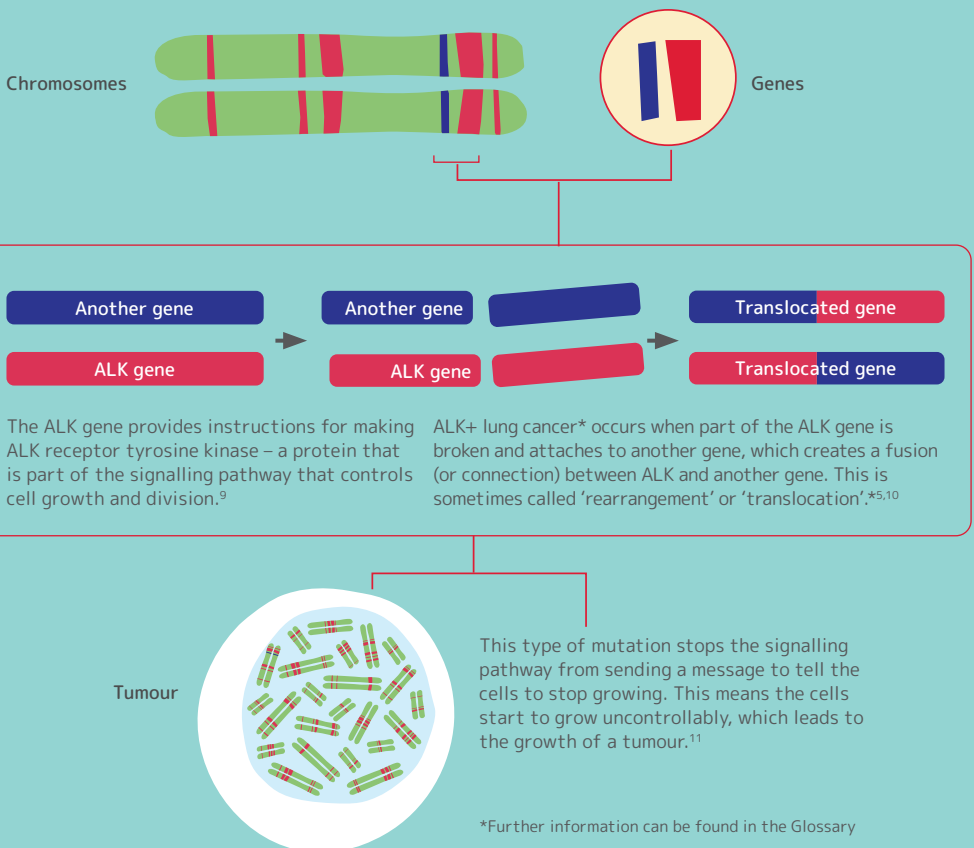
Changes that are acquired during a person’s lifetime are what’s known as ‘somatic’.\*

These genetic changes are not ‘hereditary’\* – that is to say, they are not inherited or passed through families.

Sometimes acquired, or somatic, changes in genes are caused by environmental factors, but often they are simply random events that happen without a cause.<sup>7</sup>

## So, what has happened to my ALK gene?

Chromosomes contain genes and each gene in your body contains information that is needed to make proteins. Proteins have specific jobs or functions within the body.<sup>8</sup>



# I've been diagnosed with ALK+ lung cancer. What happens next?

An ALK+ diagnosis may affect you and your family in many ways. You may all need time and space to think about how ALK+ lung cancer will impact your life.

It is not uncommon to feel shock, fear, anger or sadness when you are diagnosed with lung cancer.<sup>12</sup> A diagnosis of ALK+ lung cancer usually comes later, as it can take additional time to receive test results. It may be a surprise to learn that you have ALK+ lung cancer, leading to many new thoughts, feelings and questions.

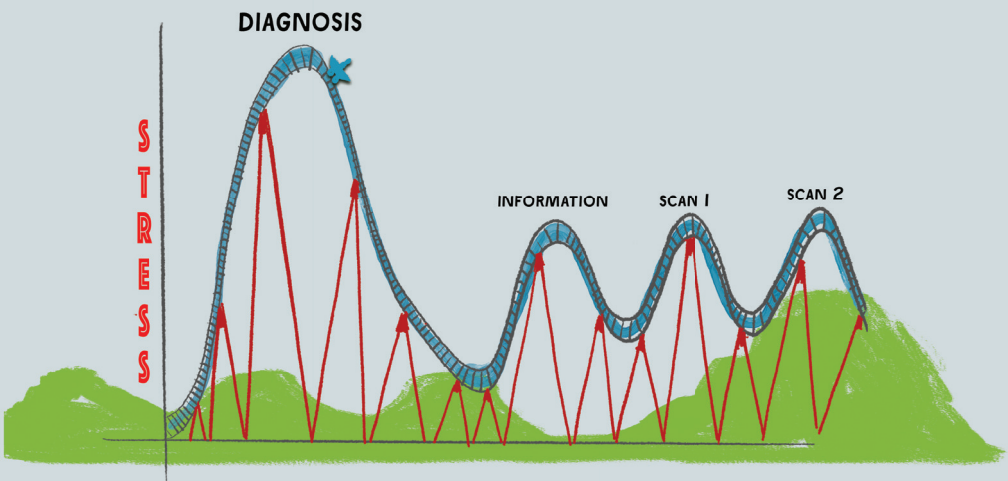
Importantly, several treatments have been developed to slow or stop the spread of ALK+ lung cancer – these are sometimes referred to as 'targeted therapies'.<sup>\*13</sup>

Your healthcare team may include a doctor who treats cancer (also called an oncologist), a doctor who treats lung conditions (also called a pneumologist, a pulmonologist or a chest expert), a specialist cancer nurse, and other experts.<sup>12</sup>

The decision about which treatment is best for you should be based on various factors, including:

- the results of your biopsy
- whether or not your disease has spread to other parts of the body, so called 'metastases'<sup>\*</sup>
- whether you have other conditions that affect your physical wellbeing
- your own preferences and priorities

It is a good idea to take time to understand what treatments are available to you and discuss these with your healthcare team.



See pages 12-13 for more information about treatments for ALK+ lung cancer.

# My preferences and priorities

You may wish to consider your own preferences and priorities as you begin your journey and as you live with ALK+ lung cancer.

As a starting point, you could think about your answers to the questions below – perhaps alongside your healthcare professional and / or carer

- Do I understand what ALK+ lung cancer is – and what it means for me?
- Do I know what treatments are available to me?
- Do I know about the possible symptoms and side effects of these treatments?
- What kind of treatment do I want?
- Do I want a treatment with as few side effects as possible?
- Do I want the longest possible life regardless of the effects of treatment?
- Do I know what help I might need during my ALK+ lung cancer journey – and how I can access it?
- How do I feel about my diagnosis?
- What can I ask my carer to do for me?
- Who else can I ask for help if I need it?
- What can I do to help myself?
- How might my diagnosis affect my relationships?
- Do I want to carry on working?
- Do I want to carry on supporting my family?
- Is there anything related to my ALK+ lung cancer I would like to know more about?
- Do I know where to go for more information?



\*Further information can be found in the Glossary

# Making healthy choices with ALK+ lung cancer



Evidence suggests that physical activity has potential benefits at all stages of cancer care. Talk about it with your doctor as it leads to benefits such as increased physical function and improved cancer-related fatigue<sup>14</sup>



Physical activity can improve your mood:<sup>14-17</sup>

- It may help you to feel more confident
- It could help if you feel anxious or depressed



Cancer treatment can make eating difficult, but good nutrition is especially important when you have cancer, as it could help you to:<sup>19</sup>

- Try to maintain your weight
- Improve your energy levels and strength
- Withstand the effects of treatment
- Lower your risk of getting an infection
- HELP YOU TO FEEL BETTER!



Eating well means taking in a variety of foods and the nutrients your body needs: proteins, fats, carbohydrates, water, vitamins and minerals<sup>19</sup>



Although many people with ALK+ lung cancer have never smoked, it is advisable to avoid second-hand smoke at work or at home. For those who do smoke, it is a good idea ask a healthcare professional for help to give up or cut down on smoking<sup>20</sup>



Making healthy choices can impact your quality of life, including your:<sup>15-18</sup>

- Physical wellbeing
- Mental wellbeing
- Social wellbeing





For people with ALK+ lung cancer, it is also important to look out for how you feel in yourself and to ask for the help you need.

You may want to find ways to conserve your energy and minimise your stress levels.<sup>19</sup> If you feel stress, or mood changes like depression and anxiety, don't be afraid to discuss these feelings with your healthcare team or the people around you.

Some people report feeling a sense of stigma when they are diagnosed. This often comes from a general lack of understanding about lung cancer,<sup>21</sup> especially of ALK+ lung cancer. This can be difficult to cope with, sometimes leading to feelings of depression or isolation.<sup>22</sup> Do not be afraid to reach out for support.

### Where can I go for support and information about my ALK+ lung cancer?

Beyond your family and friends, you may wish to seek support and guidance from healthcare professionals who understand ALK+ lung cancer or from patient support groups.

Patient support groups can be a great place to find support, information and advice about living with ALK+ lung cancer – and to connect with other people with the condition. They are made up of people with common experiences and concerns who aim to provide emotional and moral support for one another.<sup>23</sup>

#### Patient support groups may:<sup>23</sup>

- Work to educate patients, family and friends about a disease
- Share experiences of living with that disease
- Provide support and strength to their members
- Raise public awareness about a disease.

#### You may find the resources below useful:

[www.alkpositive.org.uk](http://www.alkpositive.org.uk)  
[www.alkpositive.org](http://www.alkpositive.org)  
[www.diealkpositiven.de](http://www.diealkpositiven.de)  
[www.lungcancereurope.eu](http://www.lungcancereurope.eu)  
[www.roycastle.org](http://www.roycastle.org)

Remember – even once life settles down and you fall into a pattern of treatment – you can still ask for help. Talking openly with your family, friends, healthcare professionals and patient support groups helps them to help you. It is important to remember that you are not alone.

# Symptoms and side effects of treatment for ALK+ lung cancer

People with ALK+ lung cancer may experience symptoms of lung cancer, as well as side effects related to their treatment. It is a good idea to talk to a healthcare professional about any signs, symptoms or side effects that you experience – especially if they seem to be getting worse.

## Common signs and symptoms of lung cancer include:<sup>24</sup>

- A persistent cough, or coughing up blood
- Chest pain
- Shortness of breath
- Infections that keep coming back (including bronchitis or pneumonia)
- Feeling tired or weak

Many people with ALK+ lung cancer experience intense tiredness (also called fatigue), which makes it difficult to carry out normal activities and affects quality of life\*.

People taking targeted therapy for ALK+ lung cancer may also experience side effects directly related to their treatment (which can be similar to the signs and symptoms mentioned above), such as:<sup>25,26</sup>

- Tiredness (fatigue)
- Nausea and vomiting
- Diarrhoea or constipation
- Changes in vision

Other possible side effects include: low white blood cell count, swelling / inflammation, liver problems, nerve damage (also known as neuropathy, which might feel like tingling or burning in the hands or feet) and problems with heart rhythm.<sup>25</sup>



It is advisable to let a healthcare professional know if you experience any of the symptoms or side effects mentioned above, or if they seem to be getting worse.

\*Based on feedback from patient group representatives



## ALK+ lung cancer may progress, but the science is also evolving

It is not uncommon for the cancer to start growing again or to spread to other parts of the body, even when you are receiving treatment.<sup>27</sup> Still, it is important to remember that the science is evolving, with new therapies in development and ongoing clinical research looking at alternative options for treatment.

### ALK+ lung cancer and the brain

Sometimes cancer may spread from one part of the body to another – for example, lung cancer may spread to the brain. This is still lung cancer, but is now in the brain, so is called 'brain metastases'. Although any type of cancer can spread to the brain, some types are more likely to do so – like non-small cell lung cancer.<sup>28</sup> In fact, brain metastases may affect ~50% of people with ALK+ lung cancer.<sup>29</sup> Some people with brain metastases may show symptoms, while others may not. If your cancer has spread to the brain, you may experience:<sup>28</sup>

*Headaches, weakness, sickness, mood swings / behaviour changes, fits or seizures, co-ordination problems, confusion, lethargy / tiredness, problems reading or talking.*

Let your healthcare professional know straight away if you experience any of these symptoms.

### Will I always take the same treatment?

If your cancer starts to grow while you are on treatment, you may need to change the drug therapy you are currently taking. This is also known as moving to a new 'line of treatment'.<sup>6</sup> And, the good news is that new treatment options are currently being explored in 'clinical trials'.

### Could I take part in an ALK+ clinical trial?

All potential new therapies must be carefully tested to make sure they work and are safe for use by humans.<sup>30</sup> This kind of testing is called a 'clinical trial'.

Your doctor may suggest the possibility of taking part in a clinical trial. It does not cost anything to take part in a clinical trial.

If you are considering taking part in a clinical trial, you should find out as much as you can

about the trial before deciding whether to take part:

- What are the researchers trying to find out?
- Are there any potential side effects associated with the study drug?
- What will I have to do?
- Where will I have to go?
- What are my rights and duties as a participant?
- What's the alternative if I don't want to take part?

For more information about ongoing ALK+ clinical trials, you could look at: [clinicaltrials.gov](http://clinicaltrials.gov) (search for ALK+ lung cancer)

You can also contact a local patient group to find out more about clinical trials happening near you.

# Carers – how to support someone with ALK+ lung cancer

If you are caring for someone with ALK+ lung cancer, you may be unsure what to say and do for that person, especially as you are dealing with your own emotions related to their cancer diagnosis and treatment.

## Emotional support<sup>31</sup>

Having a good understanding of the emotions a person with cancer may experience (and those you may experience as a carer) can help you provide support. There are a whole range of emotions a person may feel, including: anger, sadness, uncertainty, fear, guilt, frustration, loneliness, or grief.

Just listening to the person's thoughts and feelings is an important part of providing emotional support.

Try to be open and sensitive to how the person is feeling – and what they need – in that moment. As with any person, their emotions may change from day to day, and even from hour to hour. They may feel happy one minute and upset the next.

*Importantly, every person with cancer is different – and your loved one may not want to think about their health all the time. Try not to take it personally if they don't want to talk – they likely feel better just knowing you are there for them if needed.*

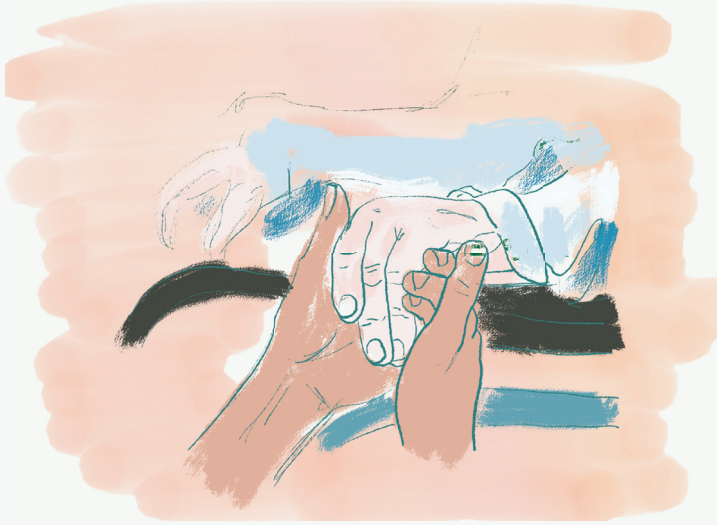
## Practical support

Some people living with ALK+ lung cancer may need practical support, as well as emotional support. Other people may want to stay as independent as possible.

Ask your loved one if there is anything specific you can do to help them. For example, you may offer to:<sup>31,32</sup>

- Make meals for them
- Do some gardening
- Help with cleaning or laundry
- Go with them to hospital appointments or blood tests
- Support them with medical decisions
- Do the shopping
- Run errands, like going to the post office
- Take the children to and from school
- Research interesting articles about ALK+ lung cancer





## Carers – how to support yourself

It may take time to adjust to the role of caring for someone with ALK+ lung cancer.<sup>31</sup> The emotional and physical demands can be challenging for even the most resilient of people – so it is a good idea to find ways to look after your own health.<sup>33</sup>

ALK+ lung cancer carers often play many roles: they may give advice, support decision-making and act as a listening ear. It is important that carers also seek support, so they are in the best position to help their loved one.

In fact, looking out for themselves and seeking the support of others is often as important for carers as it is for the person with cancer.

Carers, there are several things that you could do to help yourselves:<sup>33</sup>

- **Say ‘yes’ when people offer their help** – prepare a list of ways people could help, and when they offer, say ‘yes’
- **Try not to feel guilty** – sometimes, you may feel guilty that you can’t do everything. Choose to focus on what you can do. You are doing the best you can!
- **Be realistic in goal-setting** – break down big tasks into smaller ones. Establish a daily routine and prioritise the things you must do
- **Connect with the community** – seek out a community or patient support group where you can share experiences or ideas
- **Set your own health goals** – try to stay physically active, eat well and drink lots of water – alongside your loved one with cancer. Establish a sleep routine. And, speak to your own doctor if you need to

# Overview of treatments for people with ALK+ lung cancer

If you have ALK+ lung cancer, several specific treatments are available. You should discuss these with your healthcare team.

Traditional cancer treatments such as radiotherapy and chemotherapy may be offered:<sup>29,34</sup>

- Radiotherapy – the use of radiation, usually x-rays to treat cancer cells
- Chemotherapy – the use of anti-cancer drugs to destroy cancer cells. There are different ways of having chemotherapy drugs (at home or in the hospital) and your doctor will plan a course of treatment based on individual needs

For people with ALK+ lung cancer, treatment with traditional therapies like chemotherapy or radiation alone is generally less successful than treatment with targeted drugs.<sup>13</sup>

Targeted therapies called ‘ALK inhibitors’, also known as tyrosine kinase inhibitors (TKIs), have been developed to precisely target the mutation causing your cancer.<sup>34</sup> Access to targeted therapies varies and it is important to speak to your doctor about the treatments that are available in your country. There are opportunities to access medicines that are not licensed where you live through Compassionate Use Programs and clinical trials, your doctor will be able to help.

**In the UK, the National Institute for Care and Health Excellence (NICE) determine which treatment can be provided by the NHS and can attach conditions as to their use. Some of the treatments listed previously might not be available to everyone.**



# Advice for coping with ALK+ lung cancer treatment<sup>35</sup>

- **Be aware of changes in your health:** It may be useful to keep a diary of your emotions, physical symptoms and side effects, to share with your healthcare team – this way you can maintain a sense of control over your own life
- **Share your experiences:** Let your doctor know if you experience any side effects. You should not stop taking the medicine – talk to your doctor
- **Find out more:** If you want to know more, ask questions and find out as much as you can about ALK+ lung cancer and its treatment from reliable resources such as those highlighted in this booklet

## ALK+ lung cancer TKIs

There are older and newer types of TKIs licensed across the world, although not all of them are available in every country.

Although newer medications are, in general, more effective, many healthcare systems offer different drugs as first or second, or even third line treatments (see page 9).

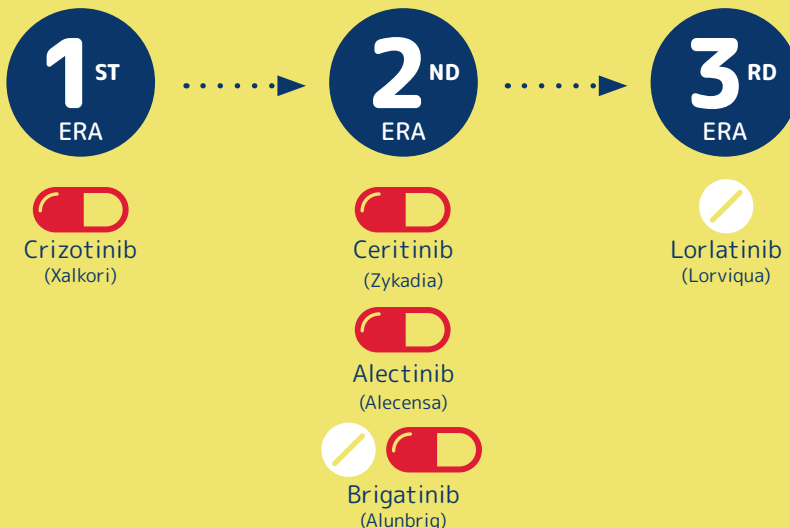
With all targeted therapies, you will have blood tests before and during treatment to check your levels of blood cells and that your liver and kidneys are functioning well.

Your doctor will advise you on how to take your TKI, for example, how many times a day, with or without food, any foods or medicines to avoid

You usually carry on taking the medication you have been prescribed for as long as it is working, unless the side effects get too bad. Always talk to your doctor first.

All TKIs work by blocking the ALK protein, thereby slowing or stopping the growth of cancer cells.

## TKI Development



# Did you know?

You can apply for a medical exemption certificate to help with the costs of prescriptions. Visit **[www.nhs.uk](http://www.nhs.uk)** for more information.

You may be eligible for Personal Independence Payment (PIP) - a benefit that helps with the extra costs of a long-term health condition. Visit **[www.gov.uk](http://www.gov.uk)** for more information.

If there is evidence of cancer in your brain, the Driver Vehicle Licensing Authority (DVLA) prohibits you from driving. We have a specific leaflet about this on our website. You can also visit **[www.gov.uk](http://www.gov.uk)** for more information.

You may be entitled to a free flu jab. Speak to your GP about this or visit **[www.nhs.uk](http://www.nhs.uk)** for more information.

If you own a smart phone, there are lots of apps available to help schedule and remind you of appointments and medication. If not, a dedicated note book or diary works just as well. It's also a good idea to note down any questions that you think of or side effects you experience between appointments.

You should have a 24/7 emergency number to contact out-of-hours or at weekends if you need advice or support outside of office hours.

If you don't have any metal in your clothing or body, you don't need to wear a hospital gown for scans.

Removing ECG electrode pads can be uncomfortable if you have hair on your chest. It may be worth considering shaving or removing hair in this area prior to ECG tests.

You are entitled to have a say in your treatment plan. Don't be afraid to research, ask questions or request information relating to your diagnosis and treatment.

You will be required to take regular blood tests during your diagnosis and treatment. There are lots of tips for making this process easier, including drinking plenty of water before tests, running your hands under warm water or requesting a nurse who is trained with a butterfly needle.

You are always entitled to have a friend, family member or chaperone with you during any consultation or meeting.

You may feel that you would like a second opinion about your treatment and all NHS patients are entitled to this.

# Notes

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# Glossary

**ALK:** A gene that provides instructions to make a protein in the body called ALK receptor tyrosine kinase.

**ALK mutation:** An ALK mutation occurs when the ALK gene is broken and attaches to another gene.

**ALK inhibitor:** A type of anti-cancer drug that specifically targets and blocks the growth (or inhibits) cancer cells caused by the ALK mutation.

**Biopsy:** A procedure that involves taking a sample of suspicious tissue from the body to test for certain changes or patterns of growth.

**Brain metastases:** When cancer that started in another part of the body – such as the lungs – spreads to the brain. It is still lung cancer, not brain cancer.

**Cancer:** A group of diseases where cells grow and reproduce uncontrollably.

**Central nervous system:** Part of the nervous system that consists of the brain and spinal cord.

**EGFR:** A gene that provides instructions for making a protein in the body called epidermal growth factor receptor. A person may have a mutation in the EGFR gene that causes EGFR+ lung cancer.

**Fatigue:** Another word for intense tiredness.

**Gene:** The building blocks of your DNA (genetic material) that determine your characteristics, e.g. hair or eye colour.

**Genetic mutation:** A fault (or change) in the DNA sequence that makes up a gene. A 'somatic' mutation is a change that is not inherited from a parent. These are usually prompted by environmental factors or may occur randomly. A 'germline' mutation occurs in the germ cells (which eventually develop into eggs or sperm) and is passed from parent to child. Gene mutations have varying effects on health, depending on where they occur.

**Hereditary:** Characteristics (or diseases) that are passed on from parents to their children in their genes.

**Lines of treatment (i.e. first-line, second-line):** The first line of treatment is the first drug given to a patient to treat a specific disease (usually accepted as the best treatment for that disease). Second-line or third-line treatments might be given if the previous treatments stop working, and so on.

**Metastases:** When cancer spreads from one part of the body to another part of the body.

**Molecular testing:** Checks for certain changes in a gene or chromosome that may cause the development of a specific disease or disorder.

**Neuropathy:** Nerve damage that can be caused by medication, tumour growth and surgery. Symptoms vary depending on the nerves affected. You may have pain, sensitivity, numbness or weakness. This is often in the hands, feet or lower legs. The nerves controlling digestion and blood pressure can also be affected, so you may have constipation, dizziness or other symptoms.

**NSCLC:** Non-small cell lung cancer – about 85% of lung cancers are NSCLC. ALK+ lung cancer is a form of NSCLC, which accounts for 4% of NSCLC cases.

**ROS1:** ROS1 is a receptor tyrosine kinase (encoded by the gene ROS1) with structural similarity to the anaplastic lymphoma kinase (ALK) protein.

**Somatic (mutations):** Genetic alterations that are acquired during a person's lifetime – they are not passed from parents to children in their genes.

**Targeted therapy:** Targeted therapy drugs interfere with the way specific cancer cells signal or interact with each other. This can stop them from growing and dividing.

**Translocation:** The movement of something from one place to another. In the case of ALK+ gene translocation, refers to the rearrangement of the ALK gene.

**Tumour:** A lump / swelling caused by the abnormal growth of tissue. Can be benign or malignant (i.e. cancerous)

**Tyrosine kinase inhibitors (TKIs):** Block chemical messengers (enzymes) called tyrosine kinases. Tyrosine kinases help to send growth signals in cells, so blocking them stops the cell growing and dividing.

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**ALK Positive UK** is a registered charity established by a group of patients and carers.

Our purposes are to provide support and advocacy and to improve the overall survival and quality of life of ALK-Positive lung cancer patients across the United Kingdom.

We are recognised by the National Institute for Health and Care Excellence (NICE) as an organisation to be consulted on new ALK positive treatments.

We have an active Facebook group for patients, family and carers. We share information on Twitter and we hold regular meetings in the UK during the year.

### Come join us at:



[www.alkpositive.org.uk](http://www.alkpositive.org.uk)



[hello@alkpositive.org.uk](mailto:hello@alkpositive.org.uk)



[facebook.com/groups/ALKPositiveUK](https://facebook.com/groups/ALKPositiveUK)



[@UKALK1](https://twitter.com/UKALK1)



[UK ALK Positive Patient Support and Advocacy Group](#)

### Acknowledgements

The booklet is based to a very large extent on one used by LuCE (Lung Cancer Europe) in collaboration with Takeda EUCAN.



Lung Cancer Europe

For more information please visit:

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The illustrations used in the booklet were drawn during the first ALK+ Lung Cancer Patient Council organised by Takeda in December 2017. They reflect the experiences of ALK+ lung cancer patients and their carers.

We would like to thank the following people for their collaboration in the development of this brochure:

Alfonso Aguarón, LuCE

Anne-Marie Baird, LuCE

Jo Ballot, Clinical Research Manager at Cancer Clinical Research Trust,

St Vincent's University Hospital

Jo Vick, Clinical Nurse, Royal Marsden Hospital

Debra Montague, ALK Positive Lung Cancer (UK)

Diego Villalón, Más que ideas

Ewelina Szymtke, LuCE

Lorraine Dallas, Roy Castle Lung Cancer Foundation

Merel Hennink, Longkanker Nederland

Regine Deniel Ihlen, LuCE

Dr Rohit Lal, Consultant Medical Oncologist, Guys and St Thomas Hospital

Shani Shilo, Israeli Lung Cancer Foundation

Stefania Vallone, LuCE

Tommy Björk, LuCE

Ulf Wiegmann, die ALKpositiven

Prepared in collaboration with  
LUCE and Takeda EUCAN

