



A Presentation by

ALK Positive Lung Cancer (UK)

A registered charity founded in 2018 by patients and families for patients and their families.

A type of non-small cell lung cancer (NSCLC)

PATIENT & FAMILY GUIDE

Understanding ALK-Positive Lung Cancer

A clear, supportive overview of what an ALK-positive diagnosis means — how it is found, how it is treated, and the reasons for hope.

A type of non-small cell lung cancer (NSCLC)

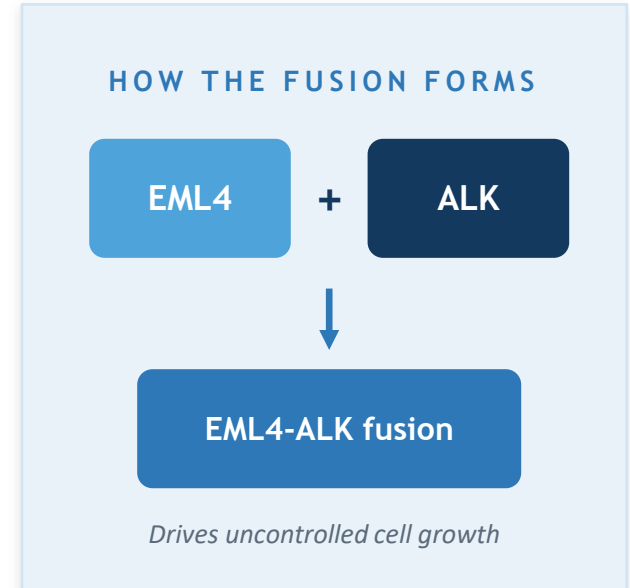


What is ALK-Positive Lung Cancer?

ALK-positive lung cancer is a **rare form of non-small cell lung cancer (NSCLC)**. It happens when the ALK gene fuses with another gene — most often (about 90%) a gene called EML4.

This fusion sends faulty signals that tell cells to divide and multiply faster than usual, which is how the cancer spreads.

It is an acquired condition — not inherited, and it cannot be passed on to children. The exact trigger is not yet known.



BY THE NUMBERS

How Common Is It?

Lung cancer is common, but the ALK-positive type is rare. These UK figures help put the diagnosis in context.

~49,000

new lung cancer cases in
the UK each year

9 in 10

of these are non-small
cell lung cancer (NSCLC)

~3%

of NSCLC cases carry the
ALK mutation

80%

of cases are found at an
advanced stage (20%
early)

Who Is More Likely to Have It?

ALK-positive lung cancer can develop in anyone, but it is seen more often in people who are:

1 Younger adults

Often diagnosed at age 52 or under, younger than the typical lung cancer patient.

2 Non-smokers

People who have never smoked, or who have smoked very little.

3 East Asian heritage

More common among people of East Asian ethnicity.

Good to know: The ALK change is acquired during life — it is not inherited and cannot be passed to your children.



DIAGNOSIS

How Is It Diagnosed?

Scans can spot lung cancer, but the ALK change can only be confirmed with genetic testing (molecular profiling).

1

Imaging

An X-ray, CT or PET scan may first identify a lung tumour.

2

Biopsy sample

A tissue biopsy from the tumour, or a blood sample (liquid biopsy), is taken.

3

Biomarker testing

The sample is checked for biomarkers that show the ALK rearrangement is present.

Treatment Depends on the Stage

The treatment offered depends on whether the cancer is caught early or has already spread.

Early stage

Stages 1, 2 & 3a

Treated with curative intent — aiming to remove or destroy the cancer:

- Surgery to remove the tumour
- Radiotherapy
- Chemotherapy
- A targeted therapy tablet may also be prescribed

Advanced stage

Stages 3b & 4

Treated to shrink tumours and hold their growth in check, mainly with oral medicines:

- Tyrosine Kinase Inhibitors (TKIs) — tablets taken by mouth
- They block the faulty ALK signals that drive growth
- Taken daily and continued for as long as they keep working

TARGETED THERAPY

Treating With TKIs

Five TKIs are approved by NICE in England and Wales for advanced ALK-positive lung cancer, with similar approvals from the Scottish Medicines Consortium.

USUAL FIRST-LINE OPTIONS AT STAGE 4

Alectinib • **Brigatinib** • **Lorlatinib**

TKIs are not a cure, but they keep a tumour in check — often for many years — lowering the chance that the cancer spreads. One day, lung cancer may be managed like other long-term conditions.



STAYING ON TOP OF IT

Monitoring and Follow-Up

Regular checks help your team see how well treatment is working and catch any changes early.

CT scans

Recommended every 3 months to track the tumour's response.

Brain MRI

At diagnosis, then every 6 months — or every 3 months if lesions are found.

ECG (heart)

A baseline before treatment, again within 4 weeks, then every 3–6 months.

Blood tests

Taken regularly to check that vital organs are not being affected.

Note: there are no national guidelines for brain imaging — the schedule above reflects best-practice recommendations from leading experts.

WHAT TO WATCH FOR

Knowing the Added Risks

ALK-positive lung cancer carries two risks worth understanding, so they can be monitored and managed.

Spread to the brain

~26% have brain tumours at the time of diagnosis

~20% more develop them within 2 years

Why a brain MRI is part of regular monitoring.

Blood clots (VTE)

~18% develop a clot within 12 months of diagnosis

~30% develop one within 5 years

Tell your team about swelling, pain or breathlessness.

Side Effects and Resistance

Side effects

- Usually much milder than chemotherapy
- Each TKI has its own effects — from mild to, occasionally, severe
- Women tend to experience more than men
- Regular blood tests protect vital organs; dose may be reduced, paused or changed

If resistance develops

- Cancers often respond very well at first, but may become resistant over time and start to grow again
- Your team may switch you to a different ALK medication
- Radiotherapy may help if growth is in only a few areas
- Chemotherapy may also be offered

REASONS FOR HOPE

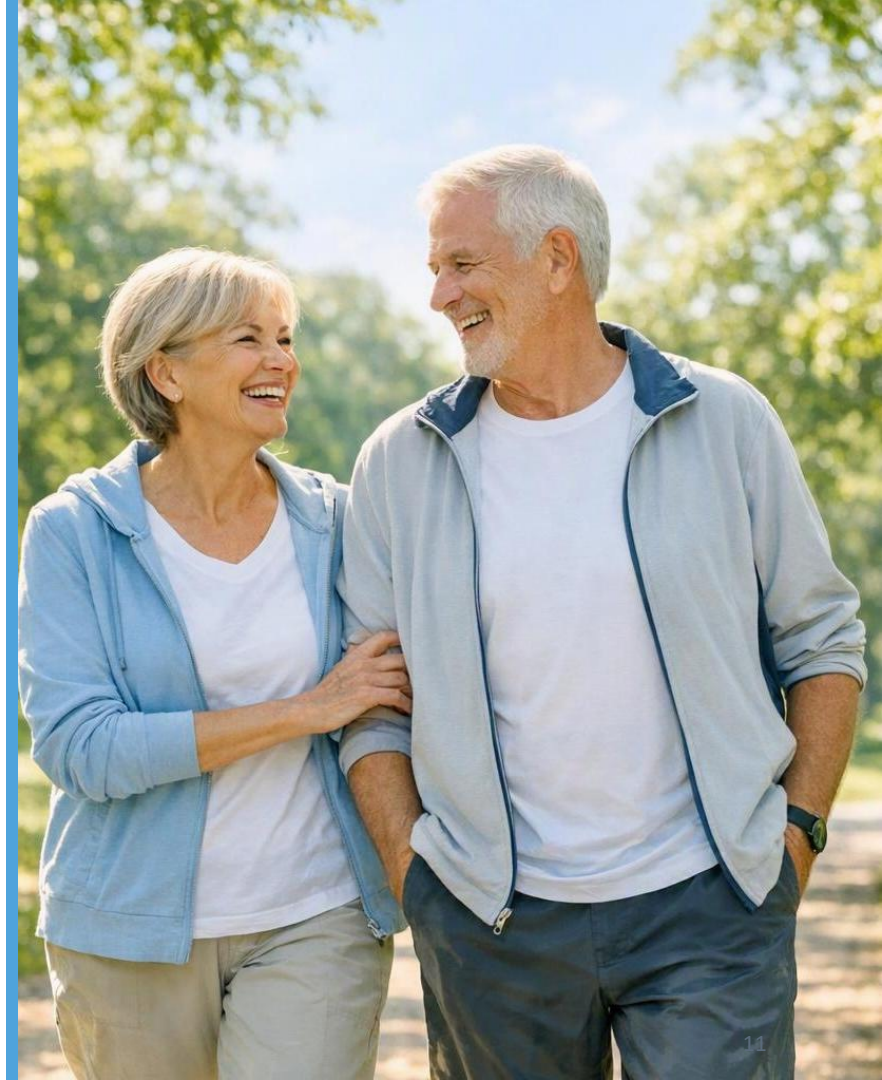
A Hopeful Outlook

Targeted therapy has transformed what an ALK-positive diagnosis can mean.

5 in 10

patients had no cancer progression after 7 years on first-line Lorlatinib (clinical trial)

TKIs offer the possibility of living progression-free for many years, with a good quality of life. *Every person is different, so outcomes cannot be predicted exactly.*



REASONS FOR HOPE

A Hopeful Outlook

Since ALK-positive NSCLC was identified about 20 years ago, an amazing number of new treatments have been introduced.

These treatments have transformed the outlook for patients.

A huge amount of research is taking place throughout the world, and it is reasonable to expect that this will lead to even more treatments in future years



IN SUMMARY

Key Things to Remember

- 1 ALK-positive lung cancer is a rare, non-inherited form of NSCLC driven by a gene fusion.
- 2 Genetic testing is essential — it confirms the ALK change so the right treatment can be chosen.
- 3 Daily targeted tablets (TKIs) keep tumours in check, often for many years.
- 4 Regular scans, MRIs, ECGs and blood tests catch changes and protect your health.
- 5 With treatment, many people live well and progression-free — there is real reason for hope.

This overview is for general information and support. It is not medical advice — always discuss your care with your healthcare team.

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www.alkpositive.org.uk