ALK Positive Lung Cancer (UK)

Supporting patients and families

A registered charity, established 2018, dedicated to everyone affected by ALK-positive lung cancer across the UK and Ireland.

AN INTRODUCTION

THE CONDITION

What is ALK-positive lung cancer?

ALK-positive lung cancer is a rare, genetically distinct form of lung cancer. It is caused by a fault in the ALK gene rather than by external lifestyle factors.

Under 52

Typical age at diagnosis — often striking people in the prime of life

Non-smokers

Most patients have no smoking history at all



A rare diagnosis, a misunderstood reality

Because so few patients fit the traditional lung cancer profile, diagnosis is too often delayed — making awareness among healthcare providers and the public essential.

Two very different journeys

Early-stage diagnosis

- Typically treated with surgery, followed by chemotherapy or an oral medication
- When caught early, there is hope that patients can be cured

Stage 4 diagnosis

80%

of patients are diagnosed at Stage 4

Currently incurable at this stage — but treatments are available that can prolong life, often for many years.

OUR MISSION

One mission – four pillars



Support

Supporting patients and their families through every stage



Empower

Empowering shared decisions about treatment



Advocate

Advocating nationally for best clinical practice



Campaign

Campaigning for earlier diagnosis

PILLAR 1 · SUPPORT

A community that understands

Patients and families don't have to face an ALK-positive diagnosis alone. Our online Support group gives members a safe space to share, ask, and be heard.

- Exchange real experiences with people who have lived it
- Give and receive day-to-day emotional support
- Get questions answered by people who understand the disease firsthand



900+

members and growing

Patients and family members supporting one another online, every single day

PILLAR 1 · SUPPORT

Bringing people together, face to face

Each quarter, we host subsidised regional lunches in 15 locations across the UK and Ireland — giving patients and families the chance to connect in person.

We believe these gatherings matter as much for mental wellbeing as for information — a chance to connect, share, and feel less alone.

15

LOCATIONS

Quarterly

Subsidised by the charity for every attendee

Across the UK and Ireland

PILLAR 1 · SUPPORT

Easing the emotional and financial burden

Living with lung cancer is stressful — emotionally and financially. We support patients and families on both fronts.



Free life coaching

A dedicated, free life coaching service available to both patients and their families — helping people navigate the emotional weight of diagnosis and treatment.



Hardship grants

Financial grants for patients facing hardship as a direct result of their diagnosis, helping ease pressure at an already difficult time.

Our national weekend conference

Once a year, patients and families gather for a national weekend conference where they hear directly from — and question — leading ALK-positive experts.

Removing cost as a barrier means no patient or family misses out on knowledge and connection that can change how they face their diagnosis.

Free to attend

For every patient, plus a companion

Travel covered

From anywhere in the UK and Ireland

Direct access to experts

A rare chance to ask questions face to face

PILLAR 2 · EMPOWER

Knowledge that enables better conversations

We help patients understand ALK-positive lung cancer in depth — so they can have meaningful, confident conversations with their healthcare providers.



Advice booklets

Clear, patient-friendly booklets that translate complex medical information into practical guidance.



A dedicated website

A wealth of trusted, regularly updated information available to patients and families whenever they need it.

PILLAR 3 · ADVOCATE

Turning lived experience into evidence

We survey our members to gather real-world data on every aspect of diagnosis and treatment — from first symptoms to long-term care.

This evidence helps us pinpoint exactly where the gaps in best-practice delivery lie — turning patient experience into a tool for change.

On the ground with clinicians

We attend conferences and meetings of oncologists and lung cancer nurses across the UK and Ireland — advocating directly for best practice in every room we're in.

PILLAR 3 · ADVOCATE

A trusted voice in the room

Our advocacy reaches beyond the clinic — into the organisations that shape treatment access and patient information.



Pharmaceutical companies

We advise pharmaceutical companies on the production of clear, accurate patient information materials.



NICE consultations

We are consulted by the National Institute for Health and Care Excellence (NICE) on new treatments for ALK-positive patients.

Anyone with lungs can get lung cancer

We campaign to raise awareness among primary healthcare providers about lung cancer in non-smokers — and use social media to reach the public directly.

- Educating GPs and primary care teams to consider lung cancer beyond the traditional smoking-history profile
- Extensive social media outreach urging the public to get symptoms checked — whatever their age or smoking status
- Earlier diagnosis means more patients reach treatable, potentially curable stages



Get checked.

Whatever your age. Whatever your smoking status.

Patient-founded. Patient-led.

By patients and families, for patients and families.

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Support Empower Advocate Campaign

www.alkpositive.org.uk