



ALK Positive Lung Cancer (UK)

# “Talking Points”

A good practice guide on what questions to ask your healthcare team

Views expressed in this document are those of the Charity and are based on the good practice that our members have experienced at the hands of leading medical lung cancer oncologists.



“ A great step forward.  
A good document that  
hits all the right spots ”

**Professor Sanjay Popat,**  
*Consultant Thoracic Medical  
Oncologist, The Royal  
Marsden Hospital*

“ Another great initiative!  
I am fully supportive  
of this excellent  
document and we will  
happily disseminate it  
to our patients ”

**Dr Fabio Gomes,**  
*Consultant Medical Oncologist,  
The Christie NHS Foundation  
Trust, Manchester*

“ This is a really useful  
booklet for the ALK+  
community, and I am  
happy that LCNUK  
nurses will be able to  
share it widely ”

**Julia McAdam,**  
*Chair, Lung Cancer Nursing UK,  
Lead Lung Cancer CNS,  
Shrewsbury & Telford Hospital  
NHS Trust*

“ This is an excellent  
document ”

**Dr Riyaz Shah,**  
*Consultant Medical Oncologist,  
Kent Oncology Centre*

**The content of this ALK Positive Lung Cancer (UK) booklet is for information only and should not be used for the diagnosis or treatment of medical conditions. We are unable to offer specific advice and, if you are worried about any symptoms, please consult your doctor.**

### Come join us at:



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



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



ALK Positive Lung Cancer - UK



@UKALK1



[alkpositivelungcanceruk](https://www.instagram.com/alkpositivelungcanceruk)



ALK Positive Lung Cancer UK

Your feedback on this guidance  
is welcome. Please email:  
[hello@alkpositive.org.uk](mailto:hello@alkpositive.org.uk)

A registered charity in England  
and Wales, registration number  
1181171. A registered charity in  
Scotland, registration number  
SC053692.

# 1. Introduction

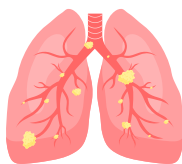
This booklet is for patients who have ALK-positive Non-Small Cell Lung Cancer (NSCLC). Its purpose is to help patients take part in decisions about their treatment.

Patients diagnosed early (Stages 1-3) will be treated with the aim of curing them.<sup>1</sup> Their treatment may include surgery, radiotherapy, chemotherapy or a targeted therapy (tablets by mouth - orally).

## Lung Cancer Stages



**Stage 1-2**, or localised disease, has not spread outside the lung.

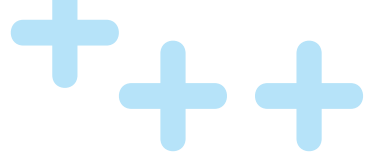


**Stage 3**, representing locally advanced disease, where the cancer has spread to the tissues surrounding the lungs.



**Stage 4**, or metastatic disease, has spread beyond the lungs to other parts of the body.

At the present time (2026), it is thought that patients diagnosed with advanced NSCLC (Stage 4) cannot be cured because the cancer has spread to other parts of the body. However, there are medicines which are taken orally that may delay the cancer growing – in some cases for many years. If the cancer grows, Stage 4 patients may also receive surgery, radiotherapy, chemotherapy, a new oral medicine or a place on a trial.<sup>2</sup>



## 2. Information

You can ask for information about your disease and treatment.

### Key questions you may wish to ask



- ▶ May I bring a relative or friend to my consultations?
- ▶ Will I be told what treatment options are available?
- ▶ Will I be told about the benefits and risks of my treatment?
- ▶ Will I be involved in decisions about my treatment?
- ▶ Will I be given written information about my cancer?
- ▶ Will I be given details about organisations that can provide support?

## 3. Quality of Life

You have the right to discuss with your healthcare providers your wishes about the quality of your life.

### Key questions you may wish to ask



- ▶ How will I be able to maintain my quality of life so that I can live as normal a life as possible?
- ▶ Will I be offered support to deal with my lung cancer diagnosis?

## 4. Experience of Healthcare Providers

ALK-positive lung cancer is relatively rare<sup>3</sup> and some oncologists may not be experienced in treating the disease.

The Charity considers that all ALK-positive patients should be able to be treated by a medical oncologist experienced in treating ALK-positive lung cancer.

The National Institute for Health and Care Excellence (NICE) guidelines state that patients should have access to a lung cancer specialist nurse.<sup>4</sup>

### Key questions you may wish to ask



- ▶ Will my diagnosis and treatment be managed by a team of healthcare providers with the knowledge and experience to give the best advice?
- ▶ What experience does my healthcare provider have in treating ALK-positive patients?
- ▶ How many ALK-positive patients are the team currently treating?
- ▶ Can I ask for a second opinion?
- ▶ Should I wish, can I be referred to a cancer centre where I can be treated by oncologists more experienced in managing ALK+ lung cancer?

## 5. Scans (CT and MRI)

It is important that Computerised Tomography (CT) scans are regularly carried out to find if your cancer has grown or spread.

Early stage NSCLC patients who have undergone treatment with the aim of curing them may go on to have follow-up scans every 2-3 months for three years – and once a year up to five years.<sup>1</sup>

Patients who are diagnosed at Stage 4 may have scans every 3 months.<sup>5</sup>

### Key questions you may wish to ask



- ▶ How often will I receive a CT scan?

ALK-positive lung cancer may spread to the brain (brain metastasis).<sup>6</sup> In a recent survey of our members, one in four Stage 4 patients reported that the cancer had spread to the brain at or soon after diagnosis.<sup>5</sup>

The Charity considers that patients should receive brain magnetic resonance imaging (MRI) at diagnosis. If the cancer is found in the brain, MRI scans should be carried out every 3 months. If cancer is not found in the brain, the Charity recommends that MRI scans should be carried out every 6 months, even if the patient is not showing symptoms.

### Key questions you may wish to ask



- ▶ How often will I receive a brain MRI?

Waiting for scan results can be stressful. It is important that you are told the result of your scans as quickly as possible.

The charity has a separate publication about the frequency of head scans, which you can refer to for more information.

### Key questions you may wish to ask



- ▶ How long after a scan will I be told of the result?
- ▶ How will I receive this information?

## 6. Electrocardiogram (ECG)

Patients taking a type of oral medication called tyrosine kinase inhibitors (TKIs) should have regular electrocardiograms (ECGs) to monitor potential cardiac side effects.<sup>2</sup> An ECG should be taken before treatment starts to establish a base line and repeated within the next four weeks to detect any early changes.

Thereafter, an ECG may be performed at 3 to 6-monthly intervals, depending on the patient's risk factors and the TKI's cardiac risk profile. High risk patients may have monthly ECGs.<sup>7</sup>

### Key questions you may wish to ask



- ▶ How often will I receive an ECG?

## 7. Cancer in the Bones

Cancer sometimes spreads to bones.<sup>8</sup>

### Key questions you may wish to ask



- ▶ If cancer is found in bones, will I receive any treatment to strengthen the bones?
- ▶ How long will I stay on the treatment?

If you have cancer in your bones you may be offered a medication to help strengthen them.

## 8. Thrombosis (DVT)

ALK-positive patients are more at risk of developing venous thromboembolism (blood clots) than other lung cancer patients, particularly in the first year of treatment.<sup>9</sup>

### Key questions you may wish to ask



- ▶ What are the symptoms of thrombosis that I should look for?
- ▶ If I develop thrombosis, how will it be treated?
- ▶ Will I have to take medication indefinitely?



## 9. Side Effects

Treatments for ALK-positive lung cancer frequently have side effects.<sup>2</sup> It is important that you can discuss these and any other matters about your treatment between meetings with your consultant. The Charity considers that each treatment centre should have a Lung Cancer Nurse Specialist who you can contact for support.

### Key questions you may wish to ask



- ▶ What side effects might I have?
- ▶ Who should I tell if I experience severe side effects?
- ▶ Do you have a Lung Cancer Nurse Specialist (LCNS) that I can contact at any time?
- ▶ If the LCNS is not available, how do I leave a message and will I be called back quickly?
- ▶ If the treatment centre doesn't have a LCNS, who can I contact between consultations?

## 10. If the Cancer Grows

Patients diagnosed at an early stage will be treated with the intention of curing them. However, in some cases, the cancer will return.<sup>10</sup>

Patients diagnosed at stage 4 are usually treated with a tyrosine kinase inhibitor (TKI) – tablets which are taken by mouth. This treatment can be very effective in delaying the development of the cancer.<sup>2</sup> However, it is likely that, at some time, the cancer will grow.<sup>11</sup>

When the cancer starts to grow, your doctor may want to take a tissue sample from the cancer (biopsy) or a blood sample (liquid biopsy), to find out whether the cancer has changed and whether the change can be targeted with a different treatment.

## Key questions you may wish to ask if the cancer grows



- ▶ What tests will be carried out, including biopsies, to find the most effective next treatment?
- ▶ Are there treatment options that I could consider?
- ▶ What are the benefits and risks of the next treatment?
- ▶ Can I get a second opinion?
- ▶ Should I be referred to a cancer centre more experienced in dealing with ALK-positive lung cancer?

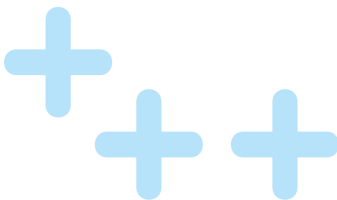
## 11. Palliative and Supportive Care

Palliative care is about improving the quality of life of patients with serious illnesses. It can include reducing side effects and pain. Palliative care can also help patients with emotional, spiritual and mental health issues. It can be used at any stage in your illness not just at end of life.<sup>12</sup>

### Key questions you may wish to ask



- ▶ If necessary, will I be given supportive and palliative care based on my individual needs?
- ▶ Can I ask to be referred to the supportive and palliative care service at any time?
- ▶ Is the supportive and palliative care service provided at home or in hospital?



## 12. Further Information

This document was prepared by ALK Positive Lung Cancer (UK). Please email us at [hello@alkpositive.org.uk](mailto:hello@alkpositive.org.uk) for further information. UK based patients and their friends and family can join our online private support group via Facebook.

Telephone : 01600 483 004

You can write to the charity via our registered address:  
ALK Positive UK, 1 Ethley Drive, Raglan, Monmouthshire, NP15 2FD

### Other sources of information and support:

**ALK Education Project**  
[www.alkknowledge.org](http://www.alkknowledge.org)

**Macmillan Cancer Support**  
[www.macmillan.org.uk](http://www.macmillan.org.uk)  
0808 808 0000

**Maggie's Cancer Centres**  
[www.maggies.org](http://www.maggies.org)  
0300 123 1801

**Roy Castle Lung Cancer Foundation**  
[www.roycastle.org](http://www.roycastle.org)  
0333 323 7200

**Cancer Research UK**  
[www.cancerresearchuk.org](http://www.cancerresearchuk.org)  
0300 123 1022

**Brains Trust**  
[www.brainstrust.org.uk](http://www.brainstrust.org.uk)  
01983 292 405

**Marie Curie**  
[www.mariecurie.org.uk](http://www.mariecurie.org.uk)  
0800 090 2309

**The Brain Tumour Charity**  
[www.thebraintumourcharity.org](http://www.thebraintumourcharity.org)  
0808 800 0004

**Radiotherapy UK**  
[www.radiotherapy.org.uk](http://www.radiotherapy.org.uk)  
0203 051 5671



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# ALK Positive UK is a registered charity established by patients and carers. Our purposes are to:



## Support

We provide a wide range of support services including a forum where patients and their families can exchange information about their diagnosis and treatment, and where they can give and receive mutual support.



## Empower

We are a source of information for patients so that they are better informed about their condition and they are empowered to ensure that their healthcare providers employ best practice.



## Advocate

We advocate on behalf of patients to ensure that they receive a high level of care wherever they live in the UK and to promote improved patient outcomes.



## Campaign

We campaign for early diagnosis and to raise awareness of lung cancer in non smokers.



### ALK Positive Lung Cancer (UK)

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Raglan  
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