



ALK Positive Lung Cancer (UK)

“Talking Points”

Questions to ask

A guide on what questions to ask your healthcare team if your cancer grows



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.



The purpose of this leaflet is to suggest to patients the questions that they might ask their oncologists in the event of their cancer growing.

The charity does not give medical advice but it aims to give patients information so that they can share in decisions about their treatment.

Further Information

This document was prepared by ALK Positive Lung Cancer (UK). Please email us at 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

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



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

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

What is Progression?

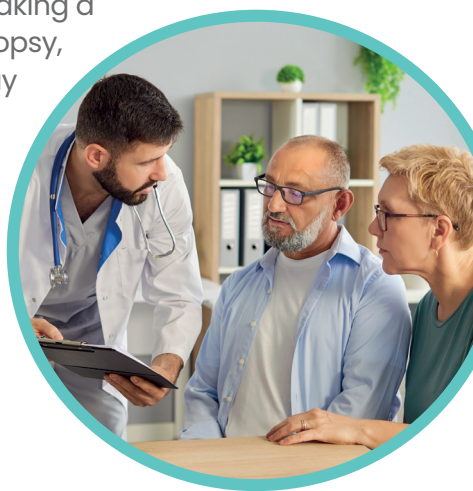
Progression is when there are signs that your cancer is growing. This marks a key event in a patient's lung cancer journey. Every effort should be made to find out the reason for the progression and to consider all possible options for future treatment.

When progression happens, it is important that patients understand their treatment options and feel involved in decisions. The progression may be in a few places in the body or brain. This is called localised progression. In other cases, the progression may be widespread and affect many places within the body or brain.

It may be possible to treat localised progression with radiotherapy or surgery.

If localised treatment is not possible, taking a sample of the cancer cells, a tissue biopsy, or a blood sample, a liquid biopsy, may be useful in deciding on the next treatment.

You may find it helpful to ask your oncologist the questions on the following page when your treatment options are being considered.



Questions to ask

your healthcare team



Write down your questions before you go and take someone with you, if possible. Make sure the appointment is with your leading consultant oncologist.

-  What **options** are you considering for further treatment?
-  Which **option** would you recommend and why?
-  Which **treatments** do you consider are **not options** and why?
-  In particular, can the progression be treated with some form of **localised treatment**?
-  If there is progression in the brain, **should this be treated** or should I switch to a targeted treatment which is more effective at **treating progression in the brain**?
-  Have these options been discussed in a **Multi-Disciplinary Team (MDT) meeting** with a surgeon and clinical oncologist?





If not, can you explain why? Oncologists will not ask an **MDT to consider every case of progression** but the oncologist should be able to explain to a patient the reasons for not doing so.



Should we be doing a **biopsy to check for changes** in my cancer that might respond to a new treatment?



If not, **can you explain** why?



Will the **biopsy be Next Generation Sequencing (NGS)**? It should be noted that NGS is not funded by the National Health Service (NHS) in all circumstances – see note below.



Do you know if there are any **clinical trials** suitable for me?



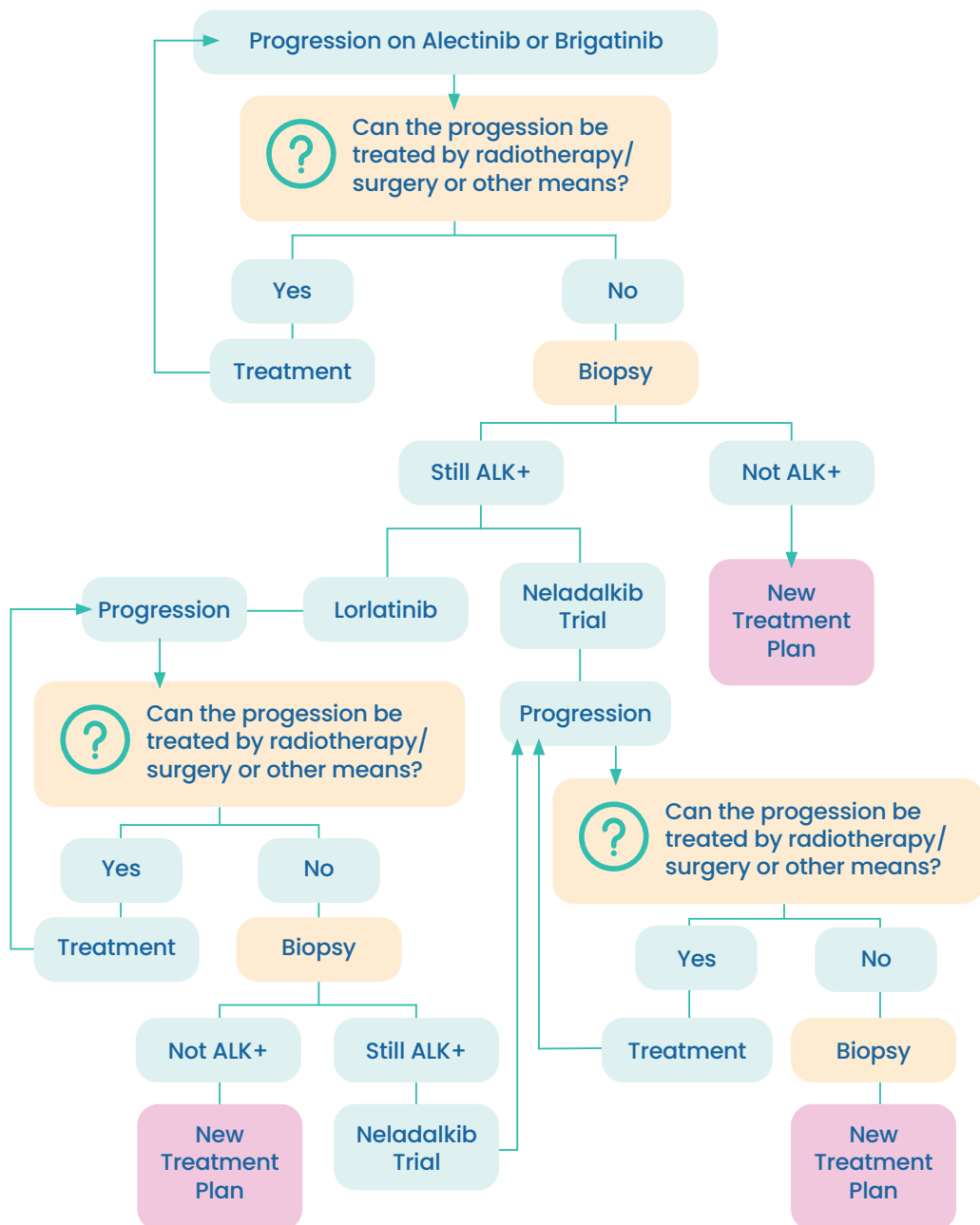
If not, **can you check**?



If I was a **private patient** would any other options be available to me?

If you are not satisfied with the answers, you can ask for a second opinion. The charity can advise on how you do this. The flowchart on the next page shows when localised therapy and biopsies should be considered. It is not possible to cover all circumstances.

This flow chart demonstrates when localised therapy and biopsies should be considered.



The charity's position on repeat biopsy and NGS

The charity considers that a biopsy for NGS when there is progression is good practice. A liquid biopsy (blood) can produce a quick result but, if this is inconclusive, a tissue biopsy should be taken, if possible.

The test may show whether there has been an “on-target” change or an “off-target” change.

“On-target” means that there has been a new mutation within the ALK gene that allows the cancer to resist the current oral targeted therapy being used. If the mutation remains ALK-positive, a switch to another oral targeted treatment may delay progression or a clinical trial designed for ALK-positive lung cancer may be appropriate.

“Off-target” means the cancer is no longer ALK-positive and has become a new mutation or has changed to small cell lung cancer. A change to another ALK targeted therapy is unlikely to work and your oncologist may consider a new treatment plan.

Only examination under a microscope (histology) and NGS will identify these changes.

The charity will consider applications under our Hardship Fund for grants to meet the cost of NGS when it is not available on the NHS and your oncologist recommends it.



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.



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