



ALK Positive Lung Cancer (UK)

Questions to ask your oncologist in the event of progression.

The purpose of this leaflet to suggest to patients the questions that they should ask their oncologists in the event of progression.

The charity does not give medical advice but it aims to empower patients so that they can have meaningful decisions about their treatment.

ALK Positive Lung Cancer (UK) (1181171 and SC053692)

1 Ethley Drive, Raglan, Monmouthshire, NP15 2FD

www.alkpositive.org.uk

07975623515

hello@alkpositive.org.uk

Chair: Debra Montague

Treasurer: Geoff Otterman

Secretary: Graham Lavender

CEO: Lynsey Conway

Manager: Rebecca Welsh

Progression 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. It is important that patients are involved in and understand treatment options when progression occurs.

Progression is when there are signs that the cancer is growing. The progression may be in a few places in the body or brain. This is called localised progression. The progression may be widespread and in many places in the body or brain.

It may be possible to treat localised progression with radiotherapy or surgery. This is called Localised Consolidated Therapy (LCT). This treatment may delay further progression.

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

Patients may find it helpful to ask their oncologist the following questions when treatment options are being considered.

Write down your questions before you go and take someone with you, if possible.

Make sure the appointment is with your leading consultant oncologist.

- 1 What options are you considering for further treatment?
- 2 Which option would you recommend and why?
- 3 Which treatments do you consider are not options and why?
- 4 In particular, can the progression be treated with some form of Local Consolidated Therapy?
- 5 Has this option been discussed in a Multi Disciplinary Team (MDT) meeting with a surgeon and clinical oncologist?
- 6 If not, why not? 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.
- 7 Should we be doing a biopsy to check for changes in the cancer that might respond to a new treatment?
- 8 If not, why not?
- 9 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.

- 10 Where LCT is not appropriate and the NGS indicates that a switch to another ALK TKI is appropriate, patients on Alectinib or Brigatinib may wish to ask their oncologist to consider a referral to a centre offering Nuvalent's Extended Access Programme for Neladalkib as an alternative to Lorlatinib.
- 11 Do you know if there are any clinical trials suitable for me?
- 12 If not, can you check?
- 13 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.

Note

The charity considers that a biopsy for NGS when there is progression is best 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 TKI designed to treat it. As the mutation remains ALK-positive, a different TKI 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 TKI will not work and your oncologist will consider a new treatment plan.

Only NGS will identify these changes. For this reason, we will consider applications under our Hardship Fund for grants to meet the cost.

The flowchart on the next page shows when local consolidated therapy should be considered and when biopsies should be taken. It is not possible to cover all circumstances.

