

ALK+

Good Practice from the Patients' Perspective

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

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

**“This is an excellent
document”**

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

**“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*



Introduction

The purpose of this document is to empower patients to be involved in and be informed about their treatment.

It is intended for use by patients diagnosed with Alk-Positive Non-Small Cell Lung Cancer (NSCLC), the majority of whom will have been diagnosed at Stage 4.

We have drawn heavily on the European Cancer Organisation's Code of Cancer Practice. Views expressed in the document are those of the Charity and reflect the good practice that our members have experienced at the hands of leading medical lung cancer oncologists.



Information

You have the right to information about your disease and treatment from your medical team and other resources, including patient and professional organisations.

Key questions you may wish to ask

- ▶ Will I be able to decide how much information I should receive about my diagnosis, treatment (including benefits and risks) and the management of my disease?
- ▶ May I bring a relative or friend to my consultations?
- ▶ Will it be explained to me what treatment options are available?
- ▶ Will I receive written information about my cancer and will I be given contact details for relevant patient-supporting organisations?

Shared Decision-making

You have the right to participate in shared decision-making with your healthcare team about all aspects of your treatment and care.

Key questions you may wish to ask

- ▶ May I discuss the approach that we will take in making decisions about my care and agree how my voice is heard?
- ▶ May we share decision-making so I feel empowered to decide on my care options?
- ▶ Does the cancer service encourage patient engagement, involvement and empowerment?



Research and Innovation

You have the right to be informed about ongoing research relevant to you and your ability and eligibility to participate in research.

Key questions you may wish to ask

- ▶ Is this cancer service active in cancer research, enrolling patients in clinical trials and supporting innovation?
- ▶ Is there a study or clinical trial in which I could participate if I am eligible and I choose to do so?
- ▶ May I go to another hospital or centre if I wish to be involved in a specific clinical research project not offered at this hospital?
- ▶ Is this treatment centre a member of the UK ALK Database?

Quality of Life

You have the right to discuss with your healthcare team your priorities and preferences to achieve the best possible quality of life.

Key questions you may wish to ask

- ▶ During my treatment, how will I be able to maintain the optimum quality of life so that I can live as normal as possible?
- ▶ Will this cancer service measure the quality of my life in any way, such as using Patient Reported Outcome Measures (PROMs)?
- ▶ Will this cancer service actively consider whether I have emotional, social or financial problems pertaining to my diagnosis or treatment?



Quality, Expertise and Outcomes

Alk+ lung cancer is relatively rare and comprises about 4% of lung adenocarcinoma. Not all oncologists will be experienced in treating Alk+ patients.

It is the view of the Charity that all Alk+ patients should have the opportunity of being treated at a centre of excellence by an experienced ALK+ medical oncologist.

Key questions you may wish to ask

- ▶ Will my diagnosis and treatment be managed by a team of healthcare professionals with the necessary expertise to give the best advice and identify the best available options for me?
- ▶ What experience does my healthcare team have in treating ALK+ patients?
- ▶ How many ALK+ patients is the team currently treating?
- ▶ Do I have the right to ask for a second opinion?
- ▶ Should I wish, can I be referred to a centre of excellence where I can be treated by more experienced oncologists?
- ▶ Does my healthcare team keep records of their clinical outcomes which I may see in an anonymised format and will I be able to compare those outcomes to those achieved by similar teams in similar institutions?



Scans

It is important that scans are regularly carried out to ascertain whether your cancer has progressed. It is the view of the Charity that a computerised tomography (CT) scan of both thorax and abdomen should be carried out every three months.

Key question you may wish to ask

- ▶ How often will I receive a CT scan?

Alk+ lung cancer frequently spreads to the brain (brain metastasis). In a recent survey of our members, 26% reported that brain metastasis was found at or shortly after diagnosis. It is the view of the Charity that patients should receive brain magnetic resonance imaging (MRI) at diagnosis and at not more than six monthly intervals (even if asymptomatic) and, if brain metastasis has been found, not more than every three months.

Key question you may wish to ask

- ▶ How often will I receive a brain MRI?

It is important that you are notified of the result of your scans quickly.

Key questions you may wish to ask

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

Cancer often spreads to bones

Key question you may wish to ask

- ▶ If cancer is found in bones, will I receive bone-strengthening medication?

Side Effects

Treatments for ALK+ lung cancer frequently have significant side effects and it is important that you can discuss these and any other matters about your treatment between meetings with your consultant. It is the view of the Charity that each treatment centre should have a Lung Cancer Nurse Specialist who you can contact at short notice.

Key questions you may wish to ask

- ▶ What side effects might I experience?
- ▶ Who should I tell if I suffer severe side effects?
- ▶ Do you have a Lung Cancer Nurse Specialist 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 if I have any concerns?

Progression

Patients diagnosed at stage 4 are usually treated with a tyrosine kinase inhibitor (TKI). This treatment can be very effective in delaying the development of the cancer. However, it is inevitable that, at some time, the cancer will progress.

Key question you may wish to ask if progression occurs

- ▶ What tests will be carried out, including biopsies, to ascertain the most effective next line of treatment?
- ▶ What clinical trials are suitable for me?
- ▶ Are there any drugs available on compassionate use/named patient use from industry that may be suitable for me?"
- ▶ If appropriate, will I be referred to a team experienced in oligo progressive disease?
- ▶ If appropriate, will I be referred to a neuro-oncology team experienced in the care of ALK+ brain disease?



Integrated Palliative and Supportive Care

You have the right to receive optimal supportive and palliative care during any part of your cancer journey. This might include help in managing physical symptoms such as pain and also may include emotional, spiritual and psychological support.

Key questions you may wish to ask

- ▶ Should it be 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?

This information has been put together by the ALK Positive Lung Cancer (UK) charity, which is run by patients of ALK positive, their family and friends. For answers to any questions you may have about ALK Positive Lung Cancer (UK), or to join our online community, contact us at hello@alkpositive.org.uk

To find out more about ALK Positive Lung Cancer (UK) visit www.alkpositive.org.uk

Please remember, you are not alone and support is always available at www.alkpositive.org.uk

