

# ALK POSITIVE PATIENT INFORMATION GUIDE

This information guide should not be considered as a replacement for medical advice.

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## ALK POSITIVE AUSTRALIA

**Anaplastic lymphoma kinase (ALK)** positive lung cancer is a type of lung cancer in which the ALK gene in the tumour cells have been rearranged. This gene rearrangement gives signals that instruct the cancer cells to divide and multiply more quickly than usual. ALK-positive lung cancer is a rare lung cancer with only up to 3-5% of all lung cancer cases found to be ALK-positive.

People with this genetic rearrangement tend to be younger than the average lung cancer patient and will often have never, or rarely, smoked. The genetic changes in the tumour cells are not hereditary and cannot be passed on to family members.

# 1. WHAT IS ALK-POSITIVE LUNG CANCER?

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## 2. HOW IS ALK-POSITIVE LUNG CANCER DIAGNOSED?

Recent advances in technology now allow for a detailed and deeper analysis of lung cancer tumour make-up. This means that when someone is diagnosed with lung cancer, special testing of the lung tissue sample called molecular testing (or biomarker testing) may be performed. This testing is done in addition to the microscopic examination of the tissue and cells that confirm the diagnosis.

Molecular testing identifies specific changes (biomarkers) in the genes of a person's cancer tumour, helping doctors select treatments that target these specific changes. Testing is typically done on a small sample of the tumour, called a biopsy, taken from the lung when the cancer is first diagnosed. Common testing methods in Australia include:



Polymerase Chain Reaction (PCR)



Fluorescence In Situ Hybridisation (FISH)



Next-Generation Sequencing (NGS)



Immunohistochemical (IHC).

Identification of ALK rearrangements is crucial for guiding treatment decisions and you should check with your healthcare team about what testing has been done. Depending on your type and stage of cancer, these tests are available on the **Medicare Benefits Schedule** (MBS); this means that most of the cost of the testing is paid for by the Australian Government and not the patient. Accurate detection ensures patients receive the most appropriate and effective treatment options available.



# 3. HOW IS ALK-POSITIVE LUNG CANCER TREATED?

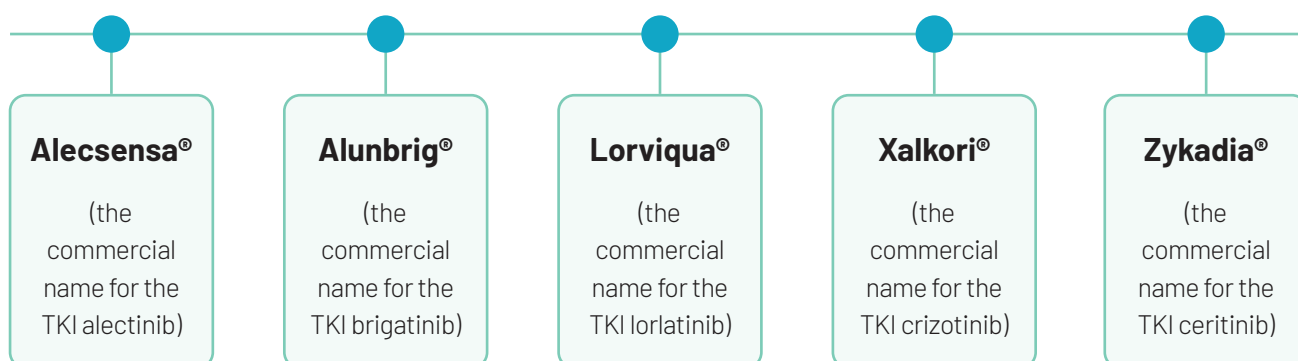
The good news is that there has been a lot of research and development of **targeted treatments**. Some of these treatments specifically target lung cancer tumours that are ALK-positive. These types of treatment are taken orally as tablets or capsules and are designed to attack cancer cells more precisely, stopping the signals that cause the cancer cells to overproduce. This means that the treatments often work better than traditional chemotherapy.

If you, or someone you know, has been diagnosed with ALK-positive lung cancer, there are targeted treatments that are currently available on the **Pharmaceutical Benefits Scheme** (PBS). This means the full price for the treatment is not paid by the patient but is subsidised by the Government.

The targeted treatments that are available on the PBS are generally given to people who have ALK-positive lung cancer that has started to spread. Currently, this includes people who have lung cancer that has spread through the lung and to the lymph nodes on the opposite side of the chest (this is called locally advanced stage 3B lung cancer) or to people who have lung cancer that has spread to other parts of the body (this is called metastatic or stage IV lung cancer). In the future, the targeted treatments may become available on the PBS for people who have ALK-positive lung cancer that has not spread through the body as much (for example people with locally advanced stage 3A lung cancer).

The currently available targeted treatments are known as Tyrosine Kinase Inhibitors (TKIs).

As of July, 2025 the following TKIs are available in Australia:



New treatments are being researched and may become available. There may also be clinical trials of new targeted treatments and treatment combinations that can be joined from within Australia. If you or someone you know has ALK-positive lung cancer, discussions with a doctor and care team can help decide which treatment options are best for each person.

## 4. WHAT IS TREATMENT LIKE?

With the recent advances in targeted treatment and quicker diagnosis of lung cancer, people with ALK-positive lung cancer can generally undertake activities that they could before being diagnosed with lung cancer. While the targeted treatments cannot currently cure the cancer, they can help people live for a long time with the cancer under control or where the signs and symptoms of the cancer have lessened significantly.

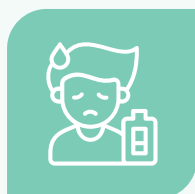
The TKIs listed above are all available in tablet or capsule form that are taken orally once or twice every day. This means that the treatment can be taken at home and visits to the doctor are only needed if there are side effects to be managed and for check-ups (scans).

More information on possible side effects and scans are below.



### Common side effects of TKI treatments

TKI treatment for ALK-positive lung cancer is generally effective at slowing down the cancer, but treatment can still cause side effects. The severity and type of the side effects may be different for every person but are generally manageable with dose adjustments or supportive care.



#### **Fatigue:**

Most people experience different degrees of fatigue (tiredness) while on TKI treatment. It is important to rest when tired; gentle exercise may help some people receiving TKIs.



#### **Gastrointestinal issues:**

Nausea (feeling sick), vomiting (being sick), decreased appetite, diarrhea and constipation are commonly experienced with TKI treatment. Medicines are available to help with these side effects.



#### **Increased cholesterol:**

TKIs can cause an increase in cholesterol in the blood, particularly in people with a history of cholesterol problems. Blood tests can monitor the levels of cholesterol and TKI treatment can be altered if needed.



#### **Kidney function:**

TKIs can impact how well the kidneys work which can lead to fluid retention in the hands, feet and legs. It is important to stay hydrated and to avoid very salty foods. Blood tests will be done to check for things like creatinine and other markers to see how well the kidneys are working.



#### **Liver function:**

Studies have shown that TKIs can increase the chances of liver damage, and this usually happens 1-3 months after starting TKI treatment. Blood tests to check liver health will be undertaken.



#### **Sun sensitivity:**

Some TKIs can increase sun sensitivity causing sunburn; even on cloudy days. Skin can become dry and itchy and so moisturisers and use of sunscreen is important.



#### **Respiratory (breathing) effects:**

Some TKIs can cause inflammation of the tissue in the lungs (known as pneumonitis). This can cause trouble breathing and a dry cough. It can be managed by adjusting the TKI treatment and/or medicines to reduce the inflammation.



#### **Neurological (brain) effects:**

Some TKIs can cause changes in cognition (understanding), thinking and behaviour (such as mood swings, anxiety and depression) and speech. Peripheral neuropathy is also possible; this is when the nervous system outside of the brain and spinal cord don't work properly. It can result in strange sensations in the hands and feet and can make balancing and walking more difficult. These side effects can be managed by altering the dose or changing the type of TKI.

**Always discuss any symptoms with your healthcare team promptly to make sure that any side effects can be managed and don't cause more problems.**

## Medical Check-ups and Scans

Alongside medical check-ups and blood tests to check for side effects, regular scans are needed to monitor how well the treatments are working. Depending on the spread and exact location(s) of the cancer, different scans may be needed. Typically, scans are performed every 3 – 6 months, but this will be decided by the doctor and the patient and based on individual requirements.

The types of scans that are commonly used are:



**Positron Emission  
Tomography (PET) scan**



**Computed  
Tomography (CT) scan**



**Magnetic Resonance  
Imaging (MRI)**

For people with ALK-positive lung cancer, they often have a chest CT and/or PET and a brain MRI at either every check-up, or every other check-up, to provide a full picture of the cancer changes to the medical team. Regular scans can help detect disease progression (spread of the cancer) or resistance to treatment (if treatment has stopped working). If progression or treatment resistance are detected early, then treatment changes may be possible and undertaken in a timely manner to provide the best outcomes for each patient.

In the case that lung cancer stops responding to targeted treatment (treatment resistance), there may be other treatment options available. These may include starting a different targeted therapy (usually another TKI), chemotherapy and/or radiation therapy. Again, it may also be possible to join a clinical trial of new treatments or combinations of treatments that can be joined from within Australia.

**If you or someone you know has been diagnosed with ALK-positive lung cancer, there is plenty of support available.**



**ALK Positive Australia ([alkpositive.org.au](http://alkpositive.org.au)) is a great place to start, with links to further information and support.**

# 5. GLOSSARY OF KEY TERMS



## **ALK (Anaplastic lymphoma kinase):**

A gene that can become rearranged in ALK-positive lung cancer, leading to uncontrolled cell growth

## **Biopsy:**

A procedure to remove a small tissue sample from the body for testing



## **Computed Tomography (CT) scan:**

Uses a combination of X-rays and computer technology to produce images of the inside of the body. The scan takes up to 10-15 minutes and may require breath holding at times. Occasionally a contrast dye may be injected to get a clearer image of the tumour cells. The appointment is usually around 30 to 60 minutes.

## **Fluorescence In Situ Hybridisation (FISH):**

Detects genetic changes in cells, specifically identifying rearrangements in the ALK gene.



## **Genetic variation/rearrangement:**

A change in the DNA sequence that may lead to cancer

## **Magnetic Resonance Imaging (MRI):**

Uses a magnetic field and computer-generated radio waves to create detailed images of the organs and tissues in your body. This type of scan is particularly used if the cancer has spread to the brain (brain metastases). The scan lasts between 15 to 90 minutes and the appointment can be up to 2 hours.



## **Medicare Benefits Schedule (MBS):**

The MBS is a list of health professional services that the Australian Government subsidises. MBS items provide patient benefits for a wide range of health services including consultations, diagnostic tests, including scans and blood tests and operations



### **Metastasis:**

The spread of cancer from its original site to other parts of the body

### **Molecular testing:**

A test used to detect specific genetic changes in cancer cells. This type of test can help decide what treatment options may be best for each person.



### **Next-Generation Sequencing (NGS):**

Is often recommended because it can test many genes at once using one sample, saving time and tissue.

### **Pharmaceutical Benefits Scheme (PBS):**

The PBS is part of the Australian Government's National Medicines Policy and provides 'timely, reliable and affordable access to necessary medicines for Australians'. Under the PBS, the government subsidises the cost of the medicine for most medical conditions, that are either used by patients at home or by specialised medical services at hospital.



### **Polymerase Chain Reaction (PCR):**

Which helps find specific genetic changes in cancer cells.

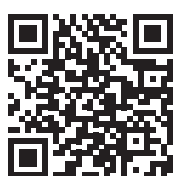
### **TKI (Tyrosine Kinase Inhibitor):**

A class of targeted therapy of drugs used to treat ALK-positive lung cancer by blocking signals that cause the cancer cells to grow



### **Positron Emission Tomography (PET) scan:**

Uses radioactive glucose (sugar) that is injected but stays in the body for a very short time. The radioactive glucose shows up brighter in areas of high activity which can indicate tumour cells and so can show how a cancer is responding to treatment. The injection of the radioactive glucose can take around an hour (with minor discomfort only) and the test itself takes about 20 minutes. The appointment can be up to 3 hours.



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