

NOT ALL LUNG CANCERS ARE THE SAME

**Your conversation
guide to lung cancer
biomarker testing
and treatment**



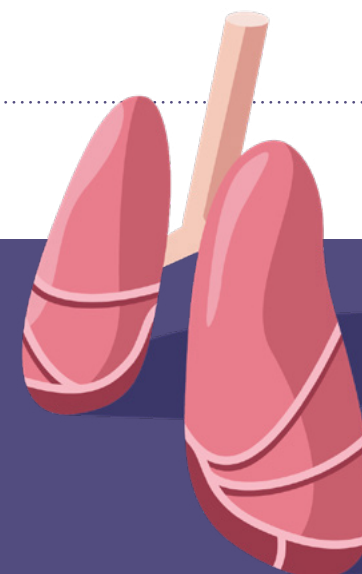
This guide was co-created by Takeda and ALK Positive Europe,
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any thoughts or
questions



INTRODUCTION

Receiving a **lung cancer** diagnosis can be a life-changing moment. It's a highly challenging time that can bring about many emotions, such as shock, fear, confusion and uncertainty. No one should ever feel they have to face this journey alone.

Lung cancer is not the same for everyone. Every diagnosis is unique and personal, requiring a tailored approach to care and treatment. This guide offers both general questions to support open communication about your care and more specific questions about your lung cancer type, biomarker testing and treatment. It is designed to provide support and clarity in the early stages after diagnosis, helping you prepare for appointments with your healthcare team and feel more confident asking the questions that matter most to you.

This resource is part of the '**Not All Lung Cancers Are the Same**' campaign, co-created by **ALK Positive Europe** and **Takeda**. It was developed with input from patient advocates and healthcare professionals across Europe, with the aim of helping you feel supported, informed, and empowered as you navigate the path ahead.

PREPARING FOR YOUR APPOINTMENTS

At every stage of your lung cancer journey, whether you're undergoing tests, receiving a diagnosis, or starting treatment, you'll be supported by a team of healthcare professionals.

Your appointments are an important opportunity to better understand your diagnosis, ask questions, and start building a care plan that reflects your needs and preferences.

PREPARING FOR YOUR APPOINTMENTS

Being well-prepared for your appointments can help you feel more confident, make sure you have the right support, and encourage clear, open communication with your healthcare team.

Here are some tips to make the most of your appointment:



Track your symptoms: In the lead-up to your appointment, take note of any symptoms and their impact on your daily life. Your healthcare team may ask how these symptoms have been progressing over time, so be ready to explain any changes.



Ask a family member or friend to support you: Appointments can be overwhelming, and it can be difficult to absorb the information you are being given. If you are comfortable, consider bringing a friend or family member along for emotional and practical support, for example helping to take notes.



Consider the aspects of your daily life where you need support: Receiving a cancer diagnosis can be a confusing and anxious time, bringing many emotions and affecting more than just your physical symptoms. Think about other areas of your life where support might be helpful, such as work responsibilities, family or caregiving duties, emotional wellbeing, finances, or maintaining your daily routine. By discussing these aspects with your team, they can help support your overall wellbeing, not just your medical treatment.

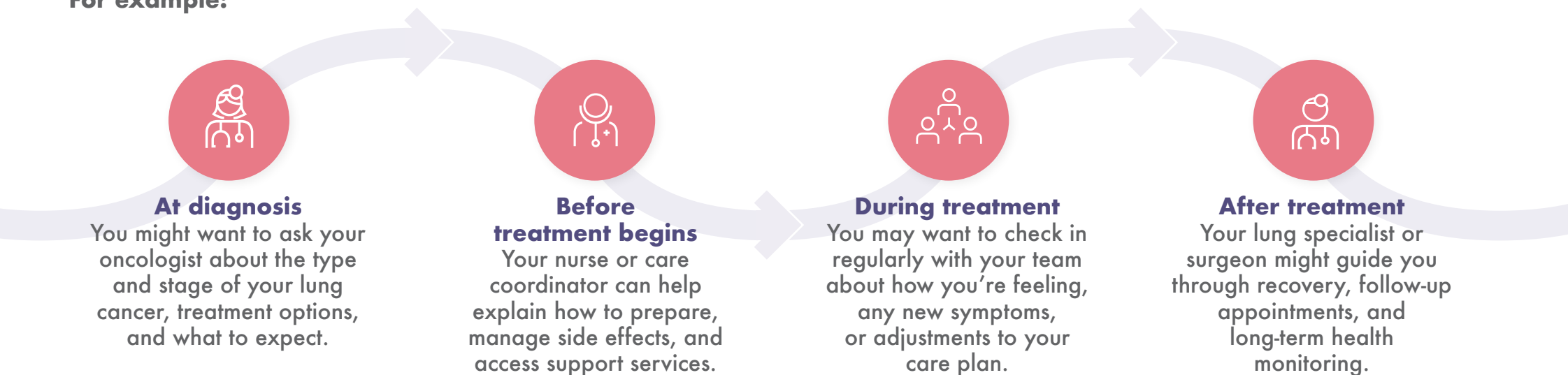


Think about the questions you would like to discuss: It's easy to forget things in the moment – use this guide to help identify the key concerns and questions you would like to address in your appointment.

DIFFERENT APPOINTMENTS ALONG YOUR JOURNEY

Your healthcare team may include an oncologist (a cancer specialist), lung specialist, nurse, surgeon, or other experts involved in your care. Depending on who you're speaking with and where you are in your treatment journey, the questions you ask - and the information you need - may change.

For example:



► Learning More About Lung Cancer

If you'd like to learn more about lung cancer testing and treatment, including some of the terms and topics mentioned in this guide, consider reading **Your guide to lung cancer biomarker testing and finding the care that fits you** – a patient information booklet co-created as part of the *Not All Lung Cancers Are the Same* campaign.

This guide offers helpful background and explanations to support your understanding and help you feel more confident during conversations with your healthcare team. It is available on the ALK Positive Europe website.

DISCUSSING YOUR DIAGNOSIS, SCANS, AND TESTS

It's completely normal to feel unsure about what to ask during your first appointment with your healthcare team. Talking with them about your diagnosis can help you gain a clearer understanding and feel more prepared for the decisions ahead.

This section contains some example questions you might want to ask during your appointments. You don't need to ask them all – choose the ones that feel most important to you and add any others that come to mind.



General diagnosis questions You might want to ask:

- What type of lung cancer do I have?
- What stage is my lung cancer?
What are the differences between the stages?
- Where exactly is the cancer in my lungs?
- How might my condition progress over time? What should I expect?
- Do you know what has caused my lung cancer?

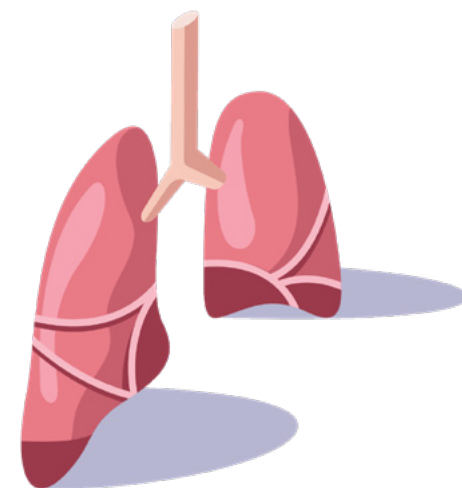


Discussing scans

Your healthcare team may recommend different tests to learn more about your cancer and guide your treatment. These may include chest x-rays, CT or MRI scans, PET scans, blood tests, tissue biopsies, or ultrasound scans.

You might want to ask:

- Will I need any scans, such as an MRI, CT or PET scan?
- What will these scans help you learn about my cancer?
- What are the differences between these scans?
- Will these scans show whether my cancer has spread?
- How often will I need to have scans?
- What are these tests looking for, and how will the results guide my treatment plan?





Discussing biomarker testing

Not all lung cancers are the same. Some types of lung cancer can be treated with medicines that are only effective for that specific type. Biomarker testing (sometimes called molecular or genetic testing) looks for certain features of your cancer that can help your healthcare team choose the treatment most likely to work for you. This is why it's important to discuss biomarker testing with your oncologist during your appointment.

You might want to ask:

- I want biomarker testing - am I eligible?
- If I'm not eligible for biomarker testing, can you help me understand why?
- How might biomarker testing influence my treatment plan?
- Could my results make me eligible for treatment specifically targeted to my type of cancer?
- What does the process of biomarker testing involve? What method is used?
- How long will it take to get the results?
- Will waiting for the results delay the start of my treatment?
- If I am eligible, will I need biomarker testing more than once?
- *If you've already had biomarker testing:* Do my test results show any specific biomarkers or genetic changes that could influence my treatment options?



Discussing genetics and family risk

If you're concerned about whether your lung cancer might be linked to inherited factors, you can ask your healthcare team for more information.

You might want to ask:

- Is there a chance that my lung cancer is linked to an inherited genetic change?
- Does my diagnosis mean my children or other family members could have a higher risk?
- Should my family members consider genetic counselling, testing, or screening?



MANAGING CONVERSATIONS AFTER DIAGNOSIS

After a lung cancer diagnosis, having open and honest conversations with your healthcare team can help you better understand your treatment options and what comes next. The questions below are suggestions to guide these discussions and support you in learning more about your care and the options available to you.



Discussing your treatment plan

Understanding your treatment plan can help you feel more informed and confident about the steps ahead. These questions can guide your conversations and help you take an active role in planning your care.

You might want to ask:

- What is the recommended treatment plan for me?
- What will my treatment plan involve – chemotherapy, targeted therapy, immunotherapy, radiation, surgery, or a combination? How is the treatment given?
- What is the goal of this treatment – curing the cancer, controlling it, or relieving symptoms?
- How have you decided on this treatment plan?
- What role can I play in deciding the course of my treatment?
- What are the potential side effects and risks associated with my treatment? How can they be managed?
- How long will my treatment last?
- Is there anything I should do to prepare for my treatment?
- How often will I need to come to the hospital?
- Where can I find more support?
- Who do I need to speak to?
- If I have problems with my treatment, who do I go to?



► Want to learn more about lung cancer types and treatments?

Check out the ***Not All Lung Cancers Are the Same patient information guide***. It includes easy-to-understand explanations and a glossary to help you make sense of new terms and treatment options.



Discussing your healthcare team

Knowing who is involved in your care and how they can support you can make the process feel less overwhelming. These questions may help you understand your healthcare team and the roles they play in your treatment.

You might want to ask:

- Who will be my main point of contact if I have questions or concerns?
- Who will make up my healthcare team, and what are their roles?
- How often will I meet different members of my team?
- Are there team members who can help me manage side effects or support my emotional well-being?

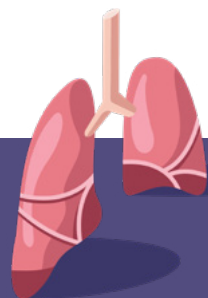


Discussing clinical trials

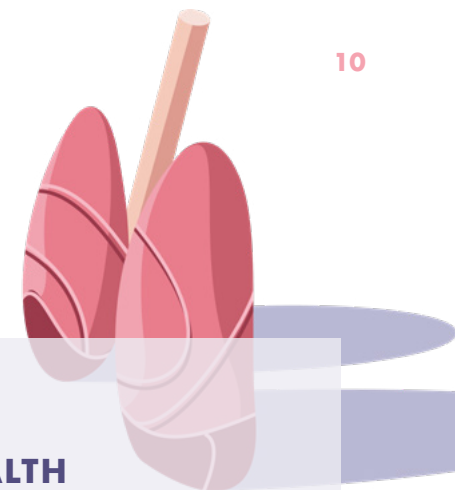
Clinical trials can provide access to new treatments that are being researched. These questions can help you understand whether a clinical trial could be an option for you.

You might want to ask:

- What kind of clinical trials exist?
- Are there any clinical trials that might be suitable for my type of lung cancer?
- Would joining a clinical trial be an option for me?
- If a trial might be appropriate, how can I learn more about it and what it would involve?



Lung cancer and its treatment can affect many aspects of daily life, not just your physical health. It's important to consider the whole picture and share any questions or concerns with your healthcare team. **You might want to ask:**



DAILY LIFE & ROUTINES

- How might treatment affect my usual day-to-day activities?
- Will I need any extra help with things like shopping or getting to appointments?
- Are there any changes I should consider making to my diet, exercise, travel plans, hobbies, or other daily habits?



EMOTIONAL & MENTAL HEALTH

- What emotional or psychological support is available for me and my family?
- Is there someone I can talk to about how I'm feeling during this time?
- Are there support groups, patient associations or counselling services?
- Are there any activities or techniques recommended to help me look after my mental health?



FAMILY, RELATIONSHIPS, & SOCIAL LIFE

- How might treatment affect time with my partner, family, friends, or loved ones?
- Are there ways to manage these changes and keep connected to the people who matter to me?
- Will I be able to manage my usual family responsibilities, such as caring for children?
- Could treatment affect my ability to have children in the future, and are there options to plan ahead?
- How can I manage intimacy changes during treatment?



WORK & FINANCES

- Will I be able to continue working during treatment, and what adjustments might help?
- When and how should I talk to my employer about my diagnosis and treatment?
- Are there support services or benefits available to help with financial concerns?
- Who can help me with paperwork, financial advice, or navigating insurance?

RESPONDING TO QUESTIONS FROM OTHERS

You may find that friends, neighbours, or colleagues ask about your diagnosis or treatment. It's okay to share as much, or as little, as you feel comfortable with.

Here are a few suggestions:

Decide what you want to share

You don't have to explain everything. A simple *"I'm focusing on my treatment right now"* is enough.

If you would like to share more, your health-care team may be able to help you prepare **You might want to ask them:**

- How can I describe my diagnosis in one sentence?
- What is a good way to explain my condition to children or teenagers?
- What should I say if someone asks me about my treatment plan or how long it will last?
- What should I say if someone asks me about what the future might look like?
- What should I say if someone asks what might have caused my lung cancer?

Set boundaries

If a question feels too personal, it's okay to explain that you would rather not talk about it at that time.

Prepare a few responses

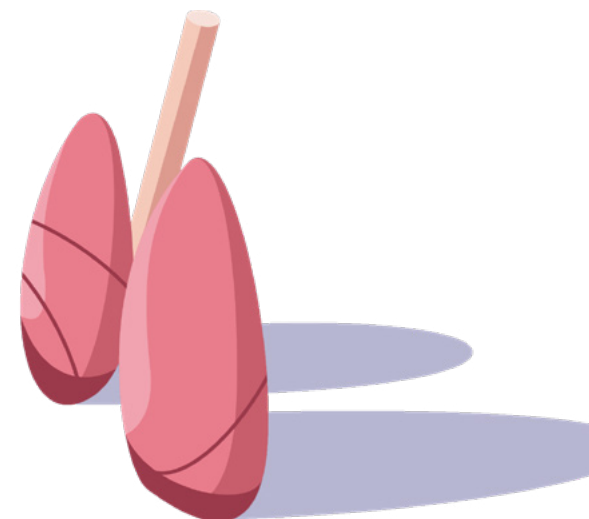
Having a couple of phrases ready can help you feel more in control, especially if you don't want to share details.

For example:

- *"Thanks for checking in - I'm taking things one step at a time."*
- *"I appreciate your concern. I'll share more when I'm ready."*

Lean on support

If you're comfortable, you could ask close friends or family help share updates, so you don't have to repeat yourself.



FOR CAREGIVERS: QUESTIONS YOU MIGHT WANT TO ASK

If you are supporting or caring for someone who has been diagnosed with lung cancer, you may have questions about how to help them through this time. These prompts are designed to guide your conversations and help you offer support with confidence and compassion.



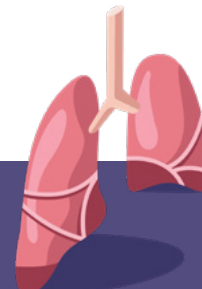
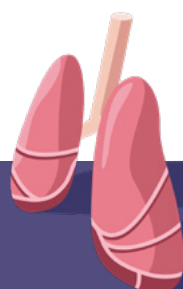
Questions to ask the person you're supporting or caring for:

- How are you feeling today – both physically and emotionally?
- Is there anything you'd like me to help with right now?
- Would you like me to come with you to appointments or take notes?
- Would you like me to keep certain information private?
- Would you like my help in sharing updates or information with family and friends?



Questions to ask their healthcare team:

- How can I best support their care at home?
- What signs, symptoms, or side effects should I keep an eye on?
- Who is the best person to contact if I have concerns between appointments?
- How can I look after my own wellbeing while supporting my loved one?
- Are there resources or support services available specifically for caregivers?
- What should I know about my loved one's treatment plan, and what might the next few weeks look like?



WHERE CAN I FIND MORE SUPPORT?

Navigating a diagnosis of lung cancer can feel overwhelming, but you don't have to do it alone. Alongside your healthcare team, many organisations are dedicated to providing support and reliable information. They may offer emotional support, practical tools, patient community connections, and educational materials to help you feel more informed about your care and the options available to you.

Consider asking your healthcare team about what's available locally and explore trusted organisations across Europe.



ALK Positive Europe

www.alkpositiveeurope.org

A patient-led association supporting people with ALK-positive lung cancer.

For more information on '**Not All Lung Cancers Are The Same**' – visit the ALK Positive Europe Resources page:
<https://alkpositiveeurope.org/resources/>



Lung Cancer Europe (LuCE)

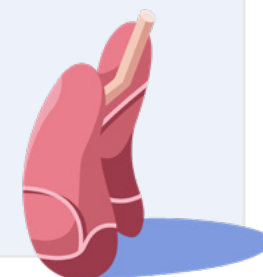
<https://www.lungcancereurope.eu>

LuCE provides a European platform for lung cancer patient advocacy associations and networks and supports the establishment of national lung cancer patient groups in those European countries where such groups do not yet exist.



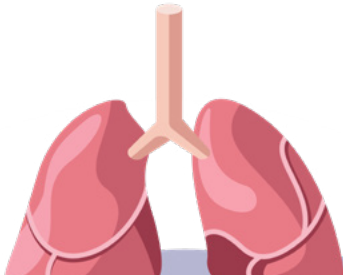
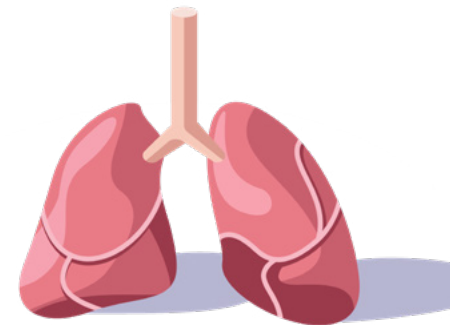
Local support organisations

Many countries have national cancer societies or lung cancer-specific groups available to provide support.



NOTES

It can be helpful to take notes before, during and after your appointments to help remember key information. Use this space to write down anything important, such as the contact details of your healthcare team, or additional questions you may have.

A stylized illustration of the human respiratory system, showing the trachea (windpipe) and the two lungs. The trachea is a vertical tube with a Y-shaped branching at the bottom. The lungs are depicted as two large, reddish-pink, lobed structures. The entire illustration is set against a light blue background.



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