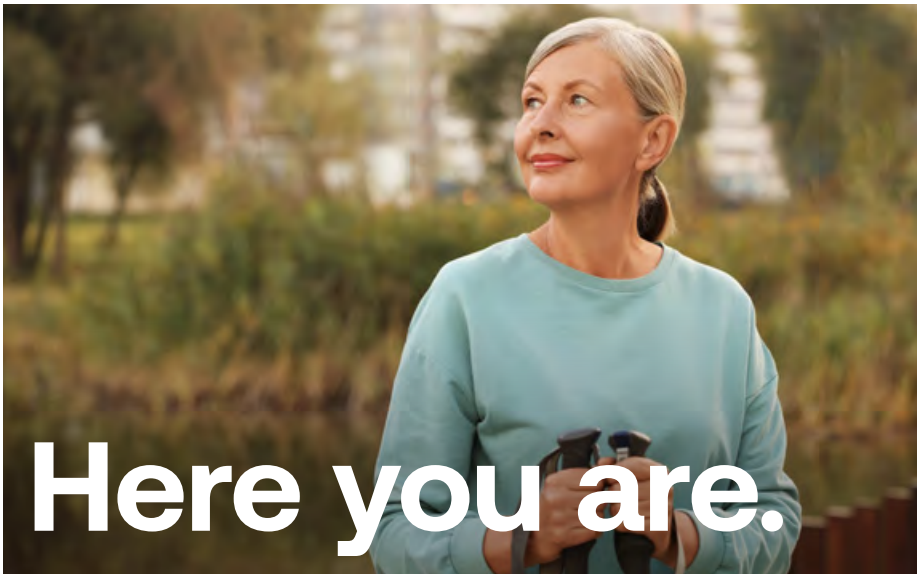


Patient Journey Handbook

for Lung Cancer





You've arrived at the right place. Receiving a diagnosis of lung cancer can feel like your world has been turned upside down. You are not alone.

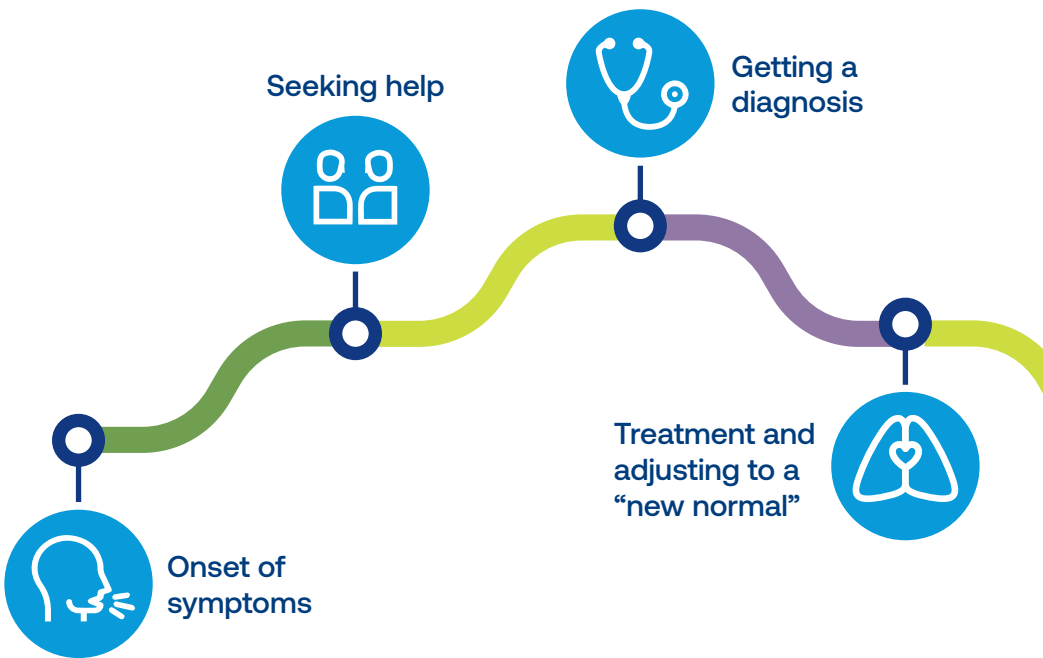
Many of us have been on the journey you are just beginning. This handbook was created by participants of the American Lung Association's Lung Cancer Patient Advisory Group for people like you. Every person's lung cancer journey is different, yet it has much in common with others. In these pages, we will share some of the lessons we've learned along the way.

How to Use This Guide

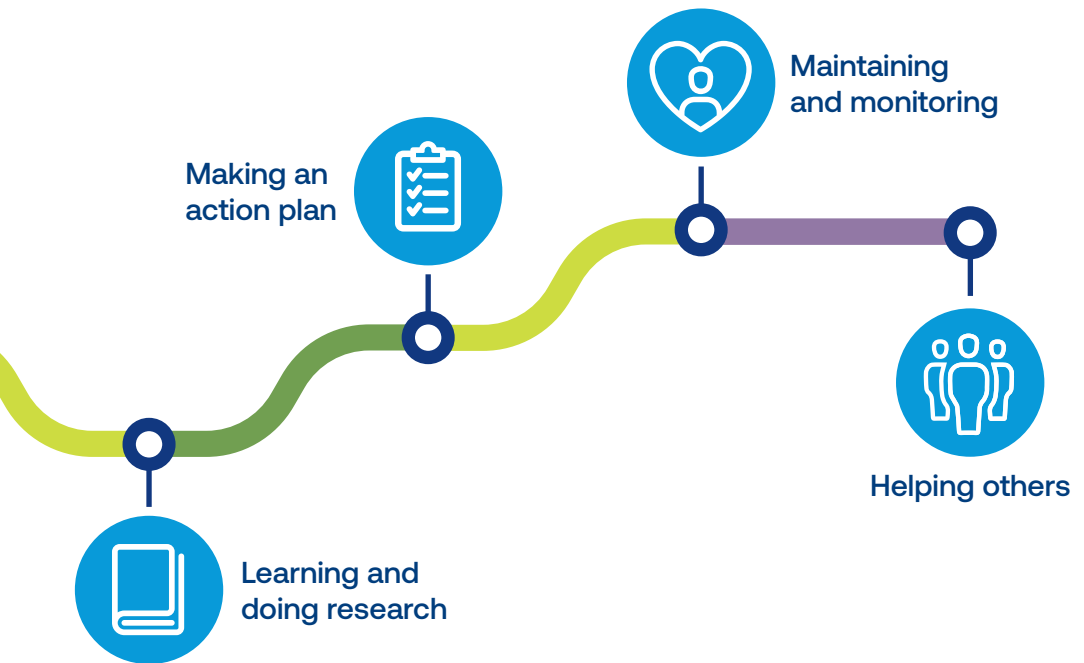
The information you find here may help you understand what to expect, how you can take control of your situation, who to speak to, and where to find reliable information, support, and assistance. Making a plan can give you structure when you feel you don't have any or don't know what to do next. We hope this handbook helps you shift into a planning frame of mind quickly so that you feel more in control. We welcome hearing from you. Let us know how we might improve upon this guide to make it more valuable for someone with your experience.

Lung Cancer is a Journey

Every person's experience with a lung cancer diagnosis, treatment, and ongoing management is unique to them. However, many patients describe moving through a common set of phases that can help you figure out where you are in the process and what you might need to do next.



Where are you on your journey?



Getting Started

Patient advisors recommend three areas to begin:

1

Find Quality Information

Gather information from your healthcare providers and other credible sources of information such as:

American Lung Association

[Lung Cancer](#) | [American Lung Association](#)

“I wanted to know everything about it, and while this sometimes felt a little obsessive, I had good reason. That knowledge gathering ended up serving me well in advocating for myself.”

2

Find Support

Support groups are available both online and in-person. Your healthcare provider or the American Lung Association can help connect you to others going through similar experiences.

[Help & Support | American Lung Association](#)

“Support groups feel like they are only for the diagnosed, and I joined a couple of forums anyway because I needed a lot of support from others who had been through the process during this time of not knowing. Their experiences helped me.”

3

Find a “New Normal”

As you schedule and attend appointments, meet new healthcare providers who will be part of your care team, and learn to prepare records and gather information, you will find yourself doing activities you’ve never had to do before. Changes in routine can be unsettling, so it’s important to give yourself time to adjust and for those around you to acknowledge that adjustment.



Onset of Symptoms

You are probably reading this handbook because you have received a diagnosis of lung cancer. It is natural to reflect on when your symptoms began and wonder what you might have done differently. If you are still at the start of your journey, you may consider the following:

Face your fear

Cancer brings out fear in all of us. Fear can feel paralyzing, preventing you from taking needed next steps, like scheduling doctor appointments or getting tests. It is important to face that fear and start thinking about steps you need to take.

Who to talk to

Your doctor(s), family, friends

What to do

1. Write down questions you may have for your doctor.
2. Schedule medical appointments and any needed tests, and start a calendar to keep track.
3. Identify the people in your life you want to inform about your diagnosis and how they might be able to help you.

“I’m not sure that it would be accurate to say that I overcame it as much as I came to live with it.”



Seeking Help

A cancer diagnosis comes with new responsibilities, ranging from scheduling and getting to and from appointments to picking up medications, deciding where to receive care, and making many other decisions. This additional work can feel overwhelming, so do not be afraid to ask for help.

What to start thinking about

- What kinds of help might you need?
- Help with scheduling appointments
- Help with travel to and from appointments
- Help understanding insurance coverage
- Help managing my symptoms
- Help organizing and accessing my medical records
- Help understanding diagnoses
- Where to find credible and reliable information
- Where to find support
- Where to find people who can explain what to expect

What to do

1. Talk to your doctor about your entire cancer care team.
2. Determine if you will need help getting to and from upcoming appointments.
3. Contact your health insurance provider.
4. Talk to your employer if you need to take time off.
5. Locate your medical records and be prepared to share them at upcoming appointments.
6. Find local lung cancer support groups if you want to join.



Diagnosis and Treatment

A diagnosis of lung cancer starts a process in which your care team helps determine the best treatment for you. It is important for you to understand their recommendations and why they think it is appropriate for you. If possible, you may want to get a second opinion and consult with your healthcare provider to better understand what your treatment will look like and what you can expect.

What to ask your care team

1. Why are we doing the treatment you recommend? What are the pros and cons?
2. What other options are available? What are their pros and cons?
3. What can I expect to feel? What are the likely side effects?
4. How will treatment affect my overall health?
5. How long will my treatments last?
6. How will we know if the treatments are working?
7. What will we do if the treatment isn't working?

“I got a second opinion. I asked questions. I learned from support group about robotic bronchoscopy, which ended up getting me the diagnosis finally, fully opening the door for surgery.”

“Stay positive and get tests promptly as ordered.”



Adjusting to a “New Normal”

Beginning treatment will disrupt your normal routines, which can feel very unsettling. Everything starts as being new and unfamiliar, but with time, you learn what to expect and you adapt. Given all these changes, it is important to plan for how treatment will affect your everyday life.

What to start thinking about

- How will my life change?
- How will this affect others?
- How will this affect my work life? Who needs to know about my treatment schedule?
- How will I get transportation to and from my appointments?
- What can I eat, and what should I avoid?
- What side effects can I expect?

What to do I need to do

1. Take care of yourself.
2. Talk about how you are feeling. Consider therapy.
3. Maintain positive attitude.
4. Become informed about treatment options, side effects, what to expect.
5. Find a routine that you're comfortable with and stick to it.
6. Keep a journal of symptoms and side effects to share with your care team.





Learning and Doing Research

It can be confusing to know where to learn more about your diagnosis, treatment options, and the latest research. While doing your own research can feel empowering, it is important to know how to distinguish between credible and non-credible sources.

Find quality information

Gather information from your healthcare providers and other credible sources of information like the **American Lung Association** (www.lung.org). Ask where to find trustworthy information.

Learning and doing research

Before researching, it is best to discuss your options with your doctor, who may already be aware of specific trials that are a good fit for you. One trusted resource is:

[Clinical Trials | American Lung Association](#)

“I focused on getting as much information as possible.”





Making an Action Plan

Patients like you have found that making an action plan is an effective way to structure their time and cope with the fear and uncertainty that comes with a lung cancer diagnosis.

Get organized

- Make a calendar to stay on top of your appointments.
- Make sure you know where your medical records can be found and bring them with you to all appointments.
- Put together a list of all your doctors and their contact information.
- Keep a list of questions for your care team.
- Identify who can help you get to and from appointments, pick up medications, assist with insurance paperwork, and help with scheduling.
- Collect information you are learning from your research to discuss with your care team.

Seek out support

Support groups are available both online and in-person. Your healthcare provider and the **American Lung Association** (www.lung.org) can help connect you to others going through similar experiences:

[Help & Support | American Lung Association](#)

“Get too busy to be afraid.”



Maintaining and Monitoring

Staying on top of your health and well-being during and after treatment is an ongoing part of the lung cancer patient journey. As you settle into your new normal, there will be new parts of your life to incorporate.

Be proactive

1. Keep advocating for yourself and learning about new research.
2. Follow your oncologist's instructions, take medications as prescribed, maintain a healthy diet, and get plenty of movement and exercise throughout your day.
3. Keep your doctor appointments faithfully and follow their advice.
4. Create time to take care of your state of mind. Relax. Meditate. Pray.
5. Continue to educate yourself.

**“You got to have a positive outlook.
You have to push on and on.”**

“I was determined to not be overwhelmed with fear of the unknown. Until it happens, there really isn't any foolproof way to not be afraid of having your cancer return. Every three months, I would just trust in my doctor and my prayers and proceed with my appointments.”

“Stay positive/keep busy to minimize ‘down time’.”



Helping Others

Some patients and survivors wish to help others who have received a lung cancer diagnosis through support groups, advocacy, and serving as members of patient advisory groups.

Consider joining a patient advisory group

To learn more about joining the American Lung Association's Lung Cancer Patient Advisory Group visit:

[Patient Advisory Groups | American Lung Association](#)

Join a support group

[Lung Cancer Support Groups | American Lung Association](#)

Sign up to volunteer

[Volunteer with American Lung Association | American Lung Association](#)

“I remind myself that no one can argue my story and it’s ok to take up space and advocate for myself and others.”

“I chose advocacy because if my cancer could be found at stage 1 then others could potentially have the same increasing their chance of survivability.”

Upcoming appointments:

Questions for my care team:
