

# Helping You Prepare for Your Next Visit

The treatment you select during your next visit should reflect your personal goals and preferences. You and your oncologist can customize your treatment, and that process starts with discussing what matters to you.

This packet includes sections for you to fill out to help you decide what matters to you in treatment. There is also one section to give to your oncologist to help him or her understand what matters to you.

## Instructions

### Step 1 | Review This Booklet

- You are NOT required to read this ahead of your next visit if you do not wish to
- Your family member or caregiver can read this for you, if you prefer

### Step 2 | Answer Questions

If you fill out pages 5 and 6 of the tool ahead of your visit, the office manager can pass your answers on to your oncologist when you arrive.

### Step 3 | Bring This to Your Visit

If you bring this to your next visit, you can use this booklet for your reference during and after the visit.

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# Timeline to Expect as You Plan Your Care

Every cancer is unique, just like every individual. Though timing varies, most people with Stage III non-small cell lung cancer (NSCLC) experience the phases below. This timeline can help you understand where you are and where you are going in your care. Right now, you are at the **Meet To Discuss Treatment Options** phase. During your next oncologist appointment, you will discuss your treatment options and may decide on what treatment option is best for you.



1 Stage: Describes the extent of lung cancer in the body.

2 Palliative Care: Treatment focused on making you feel better with no intent to cure the disease.

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# Other Goals and Needs to Discuss With Your Family and Care Team

If you have time, you can discuss these issues with your care team. Note the things that you would like to mention to your oncologist as you decide on the best treatment options for you. If you are unsure about your oncologist's guidance, **it is normal to seek a second opinion.**

**During your treatment, you might need help with activities, such as traveling to or taking notes during your appointments, cooking/cleaning, and taking care of your children/parents. Think about who could support you:**

- Adult child / parent
- Spouse / partner
- Other family member \_\_\_\_\_
- Friend \_\_\_\_\_
- Other \_\_\_\_\_

If you need help finding assistance, let your care team know as they may be able to refer you to someone.

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**Aside from your lung cancer diagnosis, you might have other things on your mind, such as:**

- How much time you or your caregiver may need to take off work
- Caring for your children / grandchildren / parents / pets
- Paying for your care or other expenses
- Other \_\_\_\_\_

Tell your care team about any of these concerns as they may be able to refer you to someone who can help.

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**Think about any important upcoming life events, such as:**

- Family events
- Work-related milestones
- Planned trips (e.g., vacation)
- Other \_\_\_\_\_

Talk to your care team about these events. They can consider them when making your care plan.

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**Think about activities that are most important to you:**

- Hobbies
- Productivity at work
- Spending time with family
- Community involvement
- Other \_\_\_\_\_

Different treatments may cause different types of side effects that could impact your day-to-day activities.

Talk to your care team about any activities that are important to you. They can let you know what to expect.

# Questions to Answer for Your Oncologist

If you would like, take 5-10 minutes to answer these questions before your next visit. Bring this sheet with you to your appointment. When you arrive, the office manager will ask for this sheet and **give it to your oncologist for him/her to read.**

## 1. How do you like making decisions about your treatment?

Please choose 1 answer:

- ☐ I prefer to make the final selection about which treatment I will receive
- ☐ I prefer to make the final selection of my treatment after seriously considering my doctor's opinion
- ☐ I prefer that my doctor and I share responsibility for deciding which treatment is best for me
- ☐ I prefer that my doctor make the final decision about which treatment will be used but seriously consider my opinion
- ☐ I prefer to leave all decisions regarding my treatment to my doctor
- ☐ I don't know

## 2. Do you have an advance directive (a legal document that explains how you want medical decisions about you to be made if you cannot make the decisions yourself)? Please choose 1 answer:

- ☐ Yes
- ☐ No
- ☐ I don't know

## 3. Who is the most important person that helps you make decisions? Please choose 1 answer:

- ☐ My spouse or partner
- ☐ My child
- ☐ My parent
- ☐ My friend
- ☐ My spiritual or religious advisor
- ☐ There is nobody else that I would include in this decision
- ☐ Other \_\_\_\_\_

## 4. Do you want to know the likelihood of your treatment being successful? Please choose 1 answer:

- ☐ Yes
- ☐ No
- ☐ I don't know

## 5. Do you have any concerns about the potential costs of your medical treatment, medication, or labs?

Please choose 1 answer:

- ☐ Yes
- ☐ No
- ☐ I don't know

## 6. Do you have any concerns about getting to your medical appointments due to things like travel or childcare?

Please choose 1 answer:

- ☐ Yes
- ☐ No
- ☐ I don't know

**7. Treatment for cancer can impact many aspects of a person's life. We are interested in what the most important things are to you when choosing a treatment. Please rank these concerns so your doctor knows what to focus on in this visit. You can also bring these concerns up again at other visits and throughout your treatment. (High Importance, Medium Importance, Low Importance)**

	High Importance	Medium Importance	Low Importance
<b>Physical Side Effects</b> (e.g., breathlessness, coughing, fatigue, rash, hair loss)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Emotional or Mental Side Effects</b> (e.g., sadness, anxiety, exhaustion, memory)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Ability to Work</b> (e.g., maintain your job and other work outside your home)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Personal Responsibilities</b> (e.g., caring for a child or parent, household responsibilities)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Logistics and Convenience</b> (e.g., transportation, lodging, appointment length, taking a pill versus intravenous medicine)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Out-of-Pocket Expenses</b> (e.g., co-pays, costs not covered by your health insurance)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Impact on Activities of Daily Life</b> (e.g., bathing, dressing, nutrition, hobbies, exercise, ability to sleep)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Burden on Family, Friends, or Care Partners</b> (e.g., how your treatment might impact other people in your life)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Important events and activities</b> (e.g., attending a wedding, travel, financial planning)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Nutrition-Related Concerns</b> (e.g., nausea, vomiting, diarrhea, weight maintenance, access to food)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Being on a Clinical Trial or Newly Approved Medications</b> (e.g., access to new treatments)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Sexual and Fertility Concerns</b> (e.g., sexual intimacy, physical appearance, pregnancy)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

# Questions to Ask Your Oncologist and Care Team

Below are questions you might want to discuss with your oncologists and care team (e.g., nurses, social workers) during your next visit. If there are specific questions that you want to discuss with someone during your next visit, please indicate those with a check mark.

## Questions to Ask Your Oncologist

### Understanding My Diagnosis and Care Goals

Check the questions you want to discuss	Questions	Notes / Answers (to track during your discussion)
<input type="checkbox"/>	<b>What type of lung cancer do I have?</b> What stage of lung cancer is it?	
<input type="checkbox"/>	<b>What clinicians might be on my care team</b> (e.g., medical, thoracic or radiation oncologist, thoracic surgeon, pulmonologist, nurse, social worker, counselor)?	
<input type="checkbox"/>	<b>What is the goal of treatment</b> (e.g., will this treatment cure me? Will it slow the growth of my cancer? Will it help me live longer? Will it help me to feel better?)?	

# My Treatment Options

Check the questions you want to discuss	Questions	Notes / Answers (to track during your discussion)
<input type="checkbox"/>	<b>What are my treatment options and why?</b> Which do you believe is the best option for me given my priorities?	
<input type="checkbox"/>	<b>Has my tumor been sent for biomarker testing to determine if targeted therapy may be a treatment option?</b> If not, is biomarker testing an option? <hr/> > <b>Biomarker testing</b> is a type of testing that looks at a sample of a person's unique cancer makeup to help choose treatments for their specific lung cancer.  > <b>Targeted therapy</b> works by targeting the cancer's specific genes, proteins, or the tissue environment that contributes to cancer growth and survival.	
<input type="checkbox"/>	<b>Are you aware of any clinical trials that might be an option for me?</b> If so, which one(s)?	



# How Well the Treatment Works

Check the questions you want to discuss	Questions	Notes / Answers (to track during your discussion)
<input type="checkbox"/>	<b>How might risk factors affect my condition and treatment</b> (e.g., exposure to toxic chemicals or gases, other lung illnesses, exposure to secondhand smoke, history of smoking)?	
<input type="checkbox"/>	<b>At what point will I know if this treatment is successful?</b> Is there anything that can help me track how my treatment is working? How long may it take to see a response?	
<input type="checkbox"/>	<b>What can I do to help make sure my treatment is as successful as possible?</b> If this treatment is not successful, what are the next steps?	

# Safety, Side Effects, and Complications

Check the questions you want to discuss	Questions	Notes / Answers (to track during your discussion)
<input type="checkbox"/>	<b>What are the most common short- and long-term complications/side effects of each treatment option</b> (e.g., shortness of breath, coughing, fatigue, pain, loss of appetite, unwanted weight loss, hair loss, rash)?	
<input type="checkbox"/>	<b>Of the symptoms I may experience, what are the signs that I should call my oncologist?</b>	

 Questions to Ask Other Members of Your Care Team (e.g., nurse, social worker)

## How, Where, and for How Long I Will Take These Treatments

Check the questions you want to discuss	Questions	Notes / Answers (to track during your discussion)
<input type="checkbox"/>	<b>How will I receive these different treatment options</b> (e.g., through an IV, a pill, radiation)?	
<input type="checkbox"/>	<b>Are there options for where I can take each of these treatments</b> (e.g., at home, at the hospital, in my oncologist's office)? If not, will I be able to access all of my treatment options at the same place?	
<input type="checkbox"/>	<b>How often will I need to take each of these treatments, and for how long?</b> How long will my visits be?	

# Impact on My Quality of Life

Check the questions you want to discuss	Questions	Notes / Answers (to track during your discussion)
<input data-bbox="235 560 289 613" type="checkbox"/>	<p><b>How might these treatment options impact my quality of life?</b></p> <ul style="list-style-type: none"> <li>• Being able to do my normal activities (e.g., dressing, bathing, using the toilet, sleeping well, cooking, driving)?</li> <li>• Being able to do what I enjoy (e.g., preparing or eating food, walking or exercising, spending time with friends)?</li> <li>• My state of mind and how I feel emotionally (e.g., irritable/depressed, exhausted, difficulty concentrating, difficulty remembering things)?</li> <li>• What steps can I take if I do experience any of these impacts?</li> </ul>	
<input data-bbox="235 1040 289 1094" type="checkbox"/>	<p><b>What alternative options are available that will help reduce my pain and symptoms, and improve my quality of life during my cancer treatment</b> (e.g., palliative care for symptom management, physical therapy, or complementary therapies such as acupuncture, meditation, or massages)?</p> <hr/> <p>➤ <b>Palliative Care:</b> A type of treatment focused on providing relief from symptoms and stress without the intent to cure the disease.</p>	
<input data-bbox="235 1370 289 1424" type="checkbox"/>	<p><b>Are there other support services I can access</b> (e.g., advice about nutrition and exercise, financial support, one-on-one or peer counseling, joining a support group)?</p>	

# Out-of-Pocket Costs to Me and My Family

Check the questions you want to discuss	Questions	Notes / Answers (to track during your discussion)
<input type="checkbox"/>	<p><b>What costs will my insurance cover?</b> What will my copay be?</p> <p>How much will these treatment options cost me out of my own pocket, including any supportive care I need (e.g., counseling, physical therapy, pain management medications)?</p>	
<input type="checkbox"/>	<p><b>Who should I talk with about options to help me with planning for these costs?</b></p> <ul style="list-style-type: none"><li>• Travel costs linked to my treatment (e.g., bus tickets, gas, parking, taxis, family travel and hotel expenses)</li><li>• Someone else to take care of my child/ elderly parent during my treatment</li><li>• Paying for treatments and medications</li></ul>	

# Other Considerations When Planning

Check the questions you want to discuss	Questions	Notes / Answers (to track during your discussion)
<input type="checkbox"/>	<p><b>What lifestyle changes might help me feel better during treatment or help the treatment work better?</b> How should I change my diet/nutrition and exercise? How do you recommend approaching quitting smoking?</p>	
<input type="checkbox"/>	<p><b>How might my treatment options impact my ability to work?</b> For example, how much time do you foresee I and/or my caregiver need to take off of work?</p> <p>Are there options that require me and/or my caregiver to take more or less time off work?</p>	
<input type="checkbox"/>	<p><b>What kind of support will my family member/caregiver need to provide for me?</b> How much time will they need to spend helping me with my care? For example:</p> <ul style="list-style-type: none"> <li>• Attending medical appointments</li> <li>• Transportation</li> <li>• Coordinating medical care and talking to the health insurance company</li> <li>• Everyday activities (e.g., cooking, bathing)</li> </ul>	
<input type="checkbox"/>	<p><b>Do I or my family member/caregiver need to learn any new skills to support me during treatment</b> (e.g., how to give an injection, how to work an oxygen tank, cleaning a port)? How can my family member/caregiver learn these new skills?</p>	

# Resources That May Be Helpful for You

A sampling of organizations that have additional resources can be found in the table below.

Organization	Website	Patient Support Number	Resources Available
American Cancer Society	<a href="http://www.cancer.org">www.cancer.org</a>	800-227-2345	   
CancerCare	<a href="http://www.cancercare.org">www.cancercare.org</a>	800-813-4673	 
Cancer Hope Network	<a href="http://www.cancerhopenetwork.org">www.cancerhopenetwork.org</a>	877-467-3838	
Clinicaltrials.gov	<a href="http://www.clinicaltrials.gov">www.clinicaltrials.gov</a>		
Cancer Support Community	<a href="http://www.cancersupportcommunity.org">www.cancersupportcommunity.org</a>	888-793-9355	 
GO2 Foundation for Lung Cancer	<a href="http://www.go2foundation.org">www.go2foundation.org</a>	800-298-2436	 
Imerman Angels	<a href="http://www.imermanangels.org">www.imermanangels.org</a>	866-463-7626	
LUNgevity	<a href="http://www.lungevity.org">www.lungevity.org</a>	844-360-5864	 
Medicine Assistance Tool	<a href="http://www.mat.org">www.mat.org</a>		
National Cancer Institute	<a href="http://www.cancer.gov">www.cancer.gov</a>	800-422-6237	
National Comprehensive Cancer Network	<a href="http://www.nccn.org">www.nccn.org</a>		
Needy Meds	<a href="http://www.needymeds.org">www.needymeds.org</a>	800-503-6897	
Patient Advocate Foundation	<a href="http://www.patientadvocate.org">www.patientadvocate.org</a>	800-532-5274	
PearlPoint Nutrition Services	<a href="http://www.pearlpoint.org">www.pearlpoint.org</a>		
The American Lung Association	<a href="http://www.lung.org">www.lung.org</a>	1-800-586-4872	  

Key



Financial Assistance  
(treatment or transportation)



Clinical Trial  
Information



Support Groups  
and Education



Nutrition Information  
or Services

## Notes

If you would like, use this page to take notes on other parts of your care. This may include other local resources identified by your nurse navigator, and other questions to ask your care team.

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.