

# DECISION AID

## STAGE IV

### Non-Small Cell Lung Cancer (NSCLC) Second- or Third-Line Chemotherapy with Erlotinib

This is a **DECISION AID** for patients who have Stage IV non-small cell lung cancer (NSCLC), and are trying to decide whether or not to take erlotinib after the first or second chemotherapy did not work or stopped working<sup>1</sup>. The goal of this **DECISION AID** is to help patients and doctors talk to each other in order to make decisions about treatment. It is based on recommendations from the American Society of Clinical Oncology's updated clinical practice guideline on stage IV NSCLC.

Use of this **DECISION AID** is voluntary. Before reading this, please discuss how you would like to receive medical information from your doctor (seeing graphs, seeing and hearing numbers, hearing words only, reading words only, etc.).

The **DECISION AID** includes information on the risks and benefits of chemotherapy and is divided into three sections:

1. Information on risks and benefits of chemotherapy
2. Help for thinking through the decision
3. Other issues to consider

The first time you read this **DECISION AID**, your doctor should be present to help you and any family members or friends you would like to include understand the information. However, you may take this document home after reviewing it with your doctor.

You may wish to think about the following before reading the **DECISION AID** and then talking to your doctor:

Are you willing to view numbers or statistics which may predict the course of advanced non-small cell lung cancer?

No  Yes

***IF YOU CHECK NO, IT IS RECOMMENDED THAT YOU NOT USE THIS DECISION AID.***

What role do you prefer in making this choice?

- I prefer to share the decision with \_\_\_\_\_
- I prefer to decide myself after hearing the views of \_\_\_\_\_
- I prefer that someone else decides
- I prefer to decide on my own

If help is desired, from whom?  Doctor  Spouse/Partner  Children  Other family member(s)  
 Other person \_\_\_\_\_

This decision aid tool is derived in part from recommendations in the American Society of Clinical Oncology Clinical Practice Guideline Update on Chemotherapy for Stage IV Non-Small Cell Lung Cancer. This decision aid tool is a practice tool based on ASCO<sup>®</sup> practice guidelines and is not intended to substitute for the independent professional judgment of the treating physician. Practice guidelines do not account for individual variation among patients. This tool does not purport to suggest any particular course of medical treatment. Use of the practice guidelines and this decision aid tool are voluntary. The practice guidelines and additional information are available at <http://www.asco.org/guidelines/nscl>. Copyright © 2009 by the American Society of Clinical Oncology. All rights reserved.

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AMERICAN SOCIETY OF CLINICAL ONCOLOGY

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# RISKS AND BENEFITS OF SECOND- OR THIRD-LINE TREATMENT WITH ERLOTINIB (treatment after initial treatment or after initial and subsequent treatment)

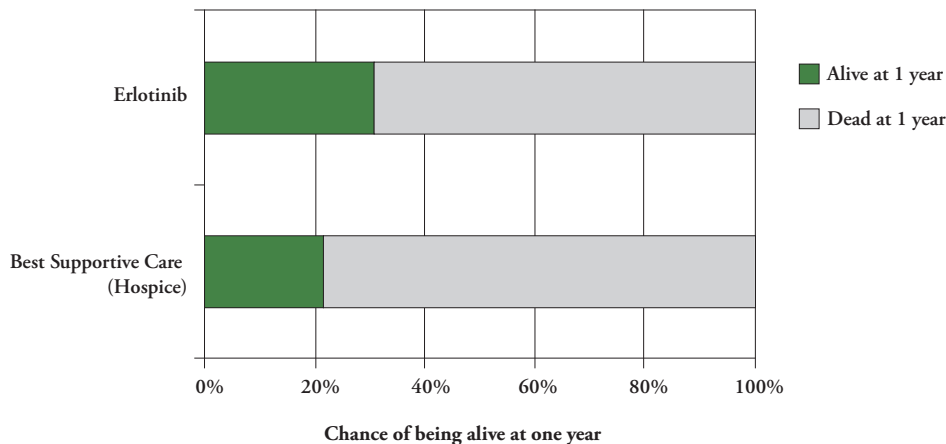
## What are my chances of being alive at one year if I take chemotherapy or do best supportive care?

Doctors sometimes tell a patient how long the average patient may live with this disease. It is important to understand that one-half of the patients will do better than this, and half will do worse. Your situation could be better or worse. Remember, you are not a “statistic” and each person has different factors that may affect his/her response. The average number is given only to help you with your own decision-making.

Erlotinib (Tarceva®) improves the chance of being alive at one year by about 9 out of 100 people. In the trial of chemotherapy comparing erlotinib with best supportive care, about 22 out of 100 people were alive after one year if they had best supportive care, and 78 out of 100 had died. Of those who received erlotinib, about 31 out of 100 were alive and 69 had died.

The average person lived 4.7 months with best supportive care, and 6.7 months if they received erlotinib. These results are shown in the graph below.

If you are having cancer-related symptoms that limit your daily activities, your chances of being alive at one year are less than described above.



1. Sources of data in this Decision Aid: Lilenbaum R, *JCO*, 2008; Shepherd F, *NEJM*, 2005; Wacker B, *Clin Cancer Res*, 2007; National Cancer Institute
2. Supportive Care is “Care given to improve the quality of life of patients....The goal of supportive care is to prevent or treat as early as possible the symptoms of a disease, side effects caused by treatment of a disease, and psychological, social, and spiritual problems related to a disease or its treatment.” Source: National Cancer Institute ([www.cancer.gov](http://www.cancer.gov))

**What is the chance of my being cured by chemotherapy?**

Unfortunately, at this time there is no known cure (where a person could be sure the cancer would go away and not return) for stage IV NSCLC. The goal may change to controlling the disease and any symptoms for as long as possible. You may want to talk with your doctor about your own chances of survival and goals of therapy. Therapies may include treatment interventions and/or other supportive interventions.

**How long will it take before my cancer may begin to grow after chemotherapy?**

In the clinical trial, the time before the cancer grew again was 2.2 months after the start of erlotinib treatment. If the cancer responded (shrank by 50% or more) which happened in 8 out of every 100 patients, this lasted 8 months.

**Will chemotherapy with erlotinib for lung cancer make my quality of life better or worse?**

About 40 out of 100 patients had relief of their primary symptoms when they took erlotinib. Cough, pain, and shortness of breath were improved with erlotinib, and were better for 1-2 months compared with placebo (inactive treatment!).

**What are the most common side effects?**

The most common side effects may include the following:

Side Effect	How likely is it?*	Additional facts
Skin rash	Less than 9 out of 100 people	The doctor can treat this. This is likely to be a sign that the erlotinib is working.
Diarrhea	Less than 6 out of 100 people	Can require hospitalization. The doctor can treat this.
Infection	Less than 2 out of 100 people	The doctor can treat this.
Interstitial Lung Disease	May be 1 out of 100; incidence is unknown <sup>3</sup>	Life-threatening

\*Number of patients experiencing these side effects out of 100 patients.

Ask your doctor for more information on side effects, how severe they are, and what can be done to help with them.

You may want to ask your doctor if there are other treatment options or clinical trials you could consider.

3. The source for interstitial lung disease is Lilenbaum R, *JCO*, 2008; the other data in this table are from Shepherd F, *NEJM*, 2005

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# WEIGHING YOUR OPTIONS

After you have spoken with your doctor about the treatment of NSCLC, the following page is intended to help you organize your thoughts in four areas. You may want to do this on your own or with someone else (for example, family, friends, or other caregivers outside of this doctor's office). Your treatment options include: 1) taking chemotherapy 2) not taking chemotherapy and 3) having best supportive care.

The next three pages include four steps:

1. What decision do you need to make?
2. What information and help do you need to make the decision?
3. What are the next steps?
4. What are other issues that I should think about?

1. **What decision do you need to make?** \_\_\_\_\_

In what time frame do you want to make a choice? \_\_\_\_\_

## 2a. What information do you need to make the decision?

Do you have enough support and advice from other people to make a choice? \_\_\_\_\_

Are you choosing your treatment option without pressure from others? \_\_\_\_\_

If you do not choose chemotherapy, would you feel guilty? \_\_\_\_\_

Do you have enough facts to make a choice? \_\_\_\_\_

Do you know who to contact and how to reach them if you have questions or problems? \_\_\_\_\_

Do you know the benefits and risks of each option? \_\_\_\_\_

Are you clear about which benefits and risks *matter most* to you? \_\_\_\_\_

In the following space, write down any additional other concerns and/or issues that you think are important to your decision (for example, your other health issues, your age, money issues, taking care of your family, etc.): \_\_\_\_\_

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**2b. What other kind of help do you need to make the decision?**

Are there other people you would like to help you make this decision?

NAME(S): \_\_\_\_\_  
 \_\_\_\_\_

How can this person or these people help you? \_\_\_\_\_  
 \_\_\_\_\_

In the following table, use the numbers to show how important each benefit and risk is to you. If you circle the number five, then the risk or benefit matters most. If you circle zero, then the risk or benefit matters least. Finally, make a star or asterisk (\*) in the column next to the benefit and/or risk(s) that you think are most likely to happen.

	<b>How much does this matter? Please circle a number: [0 (none)—5 (a lot)]</b>	<b>What is most likely to happen?</b>
<b>BENEFITS:</b>		
Decreased risk of death during the course of your illness	0 1 2 3 4 5	
Satisfaction in taking treatment that may help prolong my life	0 1 2 3 4 5	
Improvement in symptoms	0 1 2 3 4 5	
<b>RISKS:</b>		
Skin rash	0 1 2 3 4 5	
Diarrhea	0 1 2 3 4 5	
Infection	0 1 2 3 4 5	
Interstitial lung disease	0 1 2 3 4 5	

**3. Plan the next steps**

Consider planning your next steps based on your needs:

1. If you feel you do not have enough support and/or if you feel pressure from others—you may want to look for other support. Your doctor, hospital, or clinic may be able to refer you to others who could help you find additional support.
2. If you feel you do not have enough facts—you may want to get more facts. For example, you could review “What To Know: ASCO’s Guideline on Stage IV Non-Small-Cell Lung Cancer Treatment,” visit [cancer.net](http://cancer.net), visit [cancer.gov](http://cancer.gov), and/or call 1-800-4-Cancer.

**4. Are there other issues that you should think about?**

Many people use this time to reflect on their life—what they have learned and they want to share with their families, and planning for events in the future like birthdays or weddings.

Some people address spiritual issues.

Some people address financial issues, like the cost of care or a will.

Some people address Advance Directives (Living Wills). For instance, if you could not speak for yourself, who would you want to make decisions about your care?

If your heart stopped beating, or you stopped breathing, would you want to have resuscitation (CPR), or that others allow you to die naturally without resuscitation?

Some people use this time to discuss with their loved ones how they would like to spend the rest of their life. For instance, where do you want to spend your last days? Where do you want to die (at home or in a hospital setting)?

Do you want to have a hospice agency<sup>4</sup> involved, if necessary for your care?

These are all difficult but very important issues to discuss with your family, your health care professionals, and other people who may help you.

Please use the space below or another page to write any questions or concerns you have:

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4. Hospice is “a program that provides special care for people who are near the end of life and for their families, either at home, in freestanding facilities, or within hospitals.” Source: National Cancer Institute ([www.cancer.gov](http://www.cancer.gov))

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