

DECISION AID

STAGE IV

Non-Small Cell Lung Cancer (NSCLC) Third-Line and Fourth-Line Chemotherapy

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 chemotherapy after the first and subsequent treatments have not worked or stopped working¹. 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® 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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RISKS AND BENEFITS OF THIRD- OR FOURTH-LINE CHEMOTHERAPY² (treatment after initial and subsequent treatment(s))

What are my chances of being alive at one year if I take third-line or fourth-line chemotherapy or do best supportive care³?

Chemotherapy is not likely to improve the chance of being alive at one year. There are no large studies comparing chemotherapy to supportive care³ for people who have already received two or more lines of chemotherapy.

Doctors sometimes tell a patient how long the average patient may live with this disease in this situation. 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.

Most people will live several months after their second line of chemotherapy, but your time could be more or less. The average time to live in recent studies was about 5 months. Most people will live several months after their third line of chemotherapy, but your time could be more or less. The average amount of time to live has been about 4 months.

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 is to control 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 again after chemotherapy?

There are no published results of studies of third-line chemotherapy comparing chemotherapy to no chemotherapy. For patients whose cancer shrank with third-line chemotherapy, the cancer started to grow again in 2 to 3 months. There are also no published results comparing fourth-line chemotherapy to no chemotherapy. The most common time before the cancer grows again is just a few weeks.

1. Sources of data for this Decision Aid: Massarelli E, *Lung Cancer*, 2003; Noble J, *J Thorac Oncol*, 2006; Sun JM, *Jpn JCO*, 2009; National Cancer Institute
2. This Decision Aid refers to what is usually known as chemotherapy and does not include erlotinib—see the Second- and Third-Line Treatment with Erlotinib Decision Aid for a discussion of erlotinib as third-line therapy
3. 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)

Will chemotherapy make my quality of life better or worse?

There are no clinical studies which compare third-line chemotherapy to other types of treatment such as supportive care. In addition, there are no clinical studies comparing fourth-line chemotherapy to supportive care. Whether you will feel worse or better with chemotherapy depends on the type of treatment, how sick you become with chemotherapy, and if the cancer symptoms get better.

What are the most common side effects?

The most common side effects will vary with the type of treatment given. Some of the most severe side effects may require stopping, delaying, or lowering the dose of your chemotherapy. They may include the following:

- Fatigue
- Nausea with or without vomiting, usually controllable
- Hair loss
- Low white blood cell count which may lead to infection requiring antibiotics
- Numbness and pain in the hands and/or feet
- Swelling in the ankles

Ask your doctor for more information on the most common types of side effects, how severe they are, and what can be done to help them.

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

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.

	How much does this matter? Please circle a number: [0 (none)—5 (a lot)]	What is most likely to happen?
BENEFITS:		
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	
RISKS:		
Lowering of white blood count	0 1 2 3 4 5	
Fatigue which limits activity	0 1 2 3 4 5	
Nausea with or without vomiting	0 1 2 3 4 5	
Bowel problems (constipation or diarrhea)	0 1 2 3 4 5	
Appetite loss/Stopping eating	0 1 2 3 4 5	
Lowering of the red blood count	0 1 2 3 4 5	
Fever and low white blood count	0 1 2 3 4 5	
Complete hair loss	0 1 2 3 4 5	
Numbness in hands and/or feet which affects daily activity	0 1 2 3 4 5	
Hearing loss	0 1 2 3 4 5	
Life threatening complication (blood clot, bleeding or infection)	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, visit 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 agency⁴ 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:

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)

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