

DECISION AID

STAGE IV

Non-Small Cell Lung Cancer (NSCLC)

First-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 and who have not had chemotherapy before. 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 FIRST-LINE CHEMOTHERAPY (initial chemotherapy)

What are my chances of being alive at one year if I take chemotherapy or do best supportive care¹?

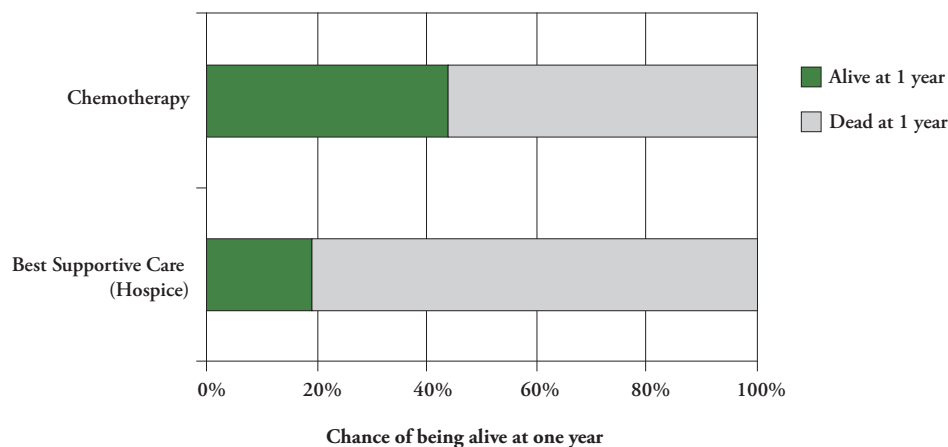
Doctors sometimes tell a patient how long the average patient may live with this disease. It is important to understand that one-half of the patients will do better than this, and half will do worse. Your situation could be better or worse. Remember, you are not a “statistic” and each person has different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

In clinical trials, the average person lived between 10 and 11 months with chemotherapy. Chemotherapy improves the chance of being alive at one year by 10 to 20 out of 100 people. 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.

In older trials that compared chemotherapy with no chemotherapy, 29 out of 100 people who took chemotherapy were alive at one year. Without chemotherapy, 20 out of 100 were alive at one year.

In more recent trials using newer chemotherapy with cisplatin (Platinol[®]) and pemetrexed (Alimta[®]) or cisplatin and gemcitabine (Gemzar[®]) for people with advanced lung cancer, 44 out of 100 people were alive after one year. At two years, 19 out of 100 people were alive.

A chart shows modern results for patients with lung cancer below.



Chemotherapy regimens often include a combination of cisplatin or carboplatin (Paraplatin[®]) with another agent. A number of drugs may be combined with cisplatin including docetaxel (Taxotere[®]), gemcitabine (Gemzar[®]), irinotecan (Camptostar[®]), paclitaxel (Taxol), pemetrexed (Alimta[®]), and vinorelbine (Navelbine[®]). The results described in this decision aid are from a representative trial. This trial used cisplatin with gemcitabine or cisplatin with pemetrexed.

1. 1. 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)

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. About 2 out of every 100 people will be alive at the end of 5 years. The goals of care include 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 supportive interventions.

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

In the most recent trials of cisplatin and pemetrexed (or cisplatin and gemcitabine), the time before the cancer grew again (time to disease progression) was 4 to 5 months.

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

In most trials of chemotherapy or no chemotherapy, the chemotherapy did not make the patients' quality of life any worse. About half of patients who take chemotherapy will have temporary relief of their worst symptoms, which may improve their quality of life.

What are the most common severe side effects?

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

Side Effect	How likely is it?*	Additional facts
Hair loss	12 to 21 of 100	Almost all patients experience some hair loss, reversible
Mouth Sores	10 to 20 of 100	Symptom relief possible
Low red blood cell count (anemia)	6 to 10 of 100	Reversible, treatable by transfusion or medicine
Nausea with or without vomiting	4 to 7 of 100	Medicine usually can help
Low platelet count (a type of blood cell important to blood clotting)	4 to 13 of 100	May or may not result in bleeding; treatable by transfusion and reducing the dose of chemotherapy
Low white blood cell count and infection requiring antibiotics	1 to 4 of 100	Reversible, treatable, but potentially life threatening
Numbness and pain in the hands and/or feet	<1 to 4 of 100	May be permanent
Chemotherapy-related death	1 of 100	

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

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 with them.

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

Sources for data in this Decision Aid: NSCLC Meta-Analysis Collaborative Group, *JCO*, 2008; Scagliotti GV, *JCO*, 2008; Schiller JH., *NEJM*, 2002; National Cancer Institute

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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.

	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:		
Mouth sores	0 1 2 3 4 5	
Complete hair loss	0 1 2 3 4 5	
Lowering of the red blood count	0 1 2 3 4 5	
Nausea with or without vomiting	0 1 2 3 4 5	
Low platelet count	0 1 2 3 4 5	
Low white blood count and fever	0 1 2 3 4 5	
Numbness in hands and/or feet which affects daily activity	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 I 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 agency² 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:

2. 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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