

DECISION AID DATA SET – Third Line

Thank you for accepting the Decision Aid Upgrade challenge.

Your task is to design a presentation of the data and statistics about treatment for late-stage lung cancer to promote shared decision-making between the clinician and the patient. Education and discussion based on this decision aid should help patients understand their prognosis, treatment options, and other sources of support.

We provide you with a data set containing information about 3 lines of chemotherapy treatment for Stage IV non-small cell lung cancer. You can assume the following:

- I: The patient already knows they have Stage IV non-small cell lung cancer
- II: At this point, chemotherapy is the only treatment option. Surgery and radiation are not options.
- III. The data set below has been verified by experts and no additional research is required.
- IV. Health literacy level is best at 5-8th grade reading level.

Not every patient is willing to view and hear survival statistics. Thus the first question under Section One is for a patient to decide if they are willing to learn about the seriousness of their illness, treatment options, and survival rates. If the patient is not ready for this discussion, we recommend that they skip to the material in Section Three: Important Life Considerations. The resources in Section Three are examples but do not constitute an exhaustive list.

**CHEMOTHERAPY CONSIDERATIONS FOR
THIRD LINE STAGE IV NON-SMALL CELL LUNG CANCER**

SECTION ONE: Information on prognosis and treatment options

1) Am I willing to view numbers or statistics which may predict the course of Stage IV non-small cell lung cancer:

No Yes

If no, then please proceed to Section Three.

If yes, please proceed with the Section One.

2) I want to have the following role in making treatment decisions:

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

Is there someone else that you want to be here to help with your understanding?

Doctor

Spouse/Partner

Children

Other family member(s)

Other person _____

3) I want to know about extra support to relieve the symptoms and address the stress of my illness.

No Yes

If no, then please proceed with Section One.

If yes, please provide information about Palliative Care (found in Section Three) and then proceed with the remainder of Section One.

4) What are the names of the drugs used in third line chemotherapy treatment of Stage IV non-small cell lung cancer?

Pemetrexed (Alimta®)

docetaxol (Taxotere)

vinorelbine (Navelbine)

- gemcitabine (Gemzar)
- Ramucirumab + docetaxol (Taxotere)

The information below presents average survival information for Stage IV non-small cell lung cancer. It is important to understand that one-half of patients will do better than this, and half will do worse. Remember, you are not a statistic and each person has different factors that may affect his/her response to chemotherapy. The average number is given only to help you with your own decision-making.

5) What is my chance of being alive at one year if I either take chemotherapy, or skip chemotherapy and pursue supportive care only (such as hospice)?

Chemotherapy is not likely to improve the chance of being alive at one year.

On average people with Stage IV non-small cell lung cancer will live about 4.7 months after their third line of chemotherapy.

Some oncologists recommend a trial of an EGFR inhibitor “targeted” drug such as erlotinib (Tarceva) as third line chemotherapy, rather than switching to hospice care. The FDA approved erlotinib (Tarceva) for this use before tests for EGFR were readily available.

People who do not have an EGFR mutation, but got erlotinib (Tarceva), lived an average of 6.7 months after this chemotherapy. Treatment with a “targeted” agent is one option available to patients who want to try more treatment, but is not recommended by the American Society of Clinical Oncology because of severe side effects.

People with Stage IV non-small cell lung cancer who did not take chemotherapy, but instead received supportive care, lived an average of 5 months after their second line of chemotherapy.

6) What is the chance of my cancer shrinking by half if I take chemotherapy?

About 2% of people will have their cancer shrink by half with additional chemotherapy, but 98% will not.

About 9% of people will have their cancer shrink by half with erlotinib (Tarceva), but 91% will not.

If you are having symptoms due to the cancer that limit your daily activities, the chances that your cancer will shrink by half are less than 2%.

7) What is the chance of my being cured by chemotherapy?

In the clinical trials, no one was cured by chemotherapy. You may want to ask your doctor about your own chances of survival and treatment goals.

8) How long will it be before my cancer begins to grow again after chemotherapy?

For people whose cancer shrank with third line chemotherapy, the cancer started to grow again in 2 to 3 months.

9) What impact will chemotherapy have on my quality of life?

There are no data comparing third line chemotherapy to other types of treatment such as hospice care. Since the chance of third line chemotherapy making the cancer shrink is so small, there is little chance it could improve quality of life.

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.

10) What are the most common side effects of chemotherapy?

The chemotherapy side effects are the same as for 1st and 2nd line chemotherapy but are more common, since the body has been exposed to prior chemotherapy.

Some of the most common ones for regular chemotherapy include the following:

- Mucositis (mouth sores) happens in 5-10% of people.
- Nausea/vomiting happens in about 40% of people, and is usually controllable.
- Alopecia (hair loss) depends on the chemotherapy. Pemetrexed (Alimta) has the lowest chance of losing your hair.
- Neutropenia (low white blood cell count) and infection requiring antibiotics 0-5% (low)
- Neuropathy (numbness and pain in the hands and feet) happens in up to half of patients. Your doctor will check for this.

Some of the most common side effects with erlotinib (Tarceva) include the following:

- Acne-like rashes in 49 to 85% of patients, which can be severe. If you have a rash, tell your doctor immediately. Moisturizers (not drying agents as used in regular acne), steroid creams, a reduced dose, and antibiotics can help.
- Diarrhea and stomach upset in 20 to 60% of patients, which can be severe.
- Fatigue in 9 to 50% of patients.
- Shortness of breath and cough in 33 to 48% of people, which can be severe. Tell your doctor if you have those symptoms. About 1 person in 100 will develop serious or fatal lung scarring.

If you decide to pursue chemotherapy, ask your doctor for a list of the most common types of side effects associated with the chemotherapy you are pursuing, including how severe they are, and what can be done to help them.

**CHEMOTHERAPY CONSIDERATIONS FOR
THIRD LINE STAGE IV NON-SMALL CELL LUNG CANCER**

SECTION TWO: My Decisions

The questions below are intended to help you organize your thoughts after you have spoken with your doctor about your prognosis and treatment options. You may want to complete this on your own or with someone else (for example, family, friends, or other caregivers outside of your doctor's office).

1. What decision do you need to make?

- I am trying to decide whether or not to take chemotherapy
- I am trying to decide among different chemotherapy options
- I am trying to better understand my prognosis
- I am trying to understand the resources I might need based on my illness

2. By when do you need to make it? _____

3. Do you have enough facts to make a decision?

- No Yes

If no, what additional information do you need? _____

If yes, please proceed.

4. Do you have enough support and advice to make a decision?

- No Yes

If no, what additional support do you need? _____

If yes, please proceed.

5. Do you know the benefits and risks of taking chemotherapy vs. skipping chemotherapy?

- No Yes

If no, what additional information do you need? _____

If yes, please proceed.

6. Are you clear about which benefits and risks ***matter most*** to you?

- No Yes

If no, what additional information do you need? _____

If yes, please proceed.

7. 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.

How much does this matter? Please circle a number: [0 (none)—5 (a lot)]

BENEFITS OF CHEMOTHERAPY:

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 OF CHEMOTHERAPY:

Complete hair loss	0 1 2 3 4 5
Fatigue which limits activity	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
Hearing loss	0 1 2 3 4 5
Lowering of the 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
Bowel problems (constipation or diarrhea)	0 1 2 3 4 5
Appetite loss / stopping eating	0 1 2 3 4 5
Lowering of white blood count	0 1 2 3 4 5

8. In the following space, write down any additional 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.):

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

No Yes

If no, who can help you find the right person and their contact information?

If yes, feel free to use this area to list important contacts.

CHEMOTHERAPY CONSIDERATIONS FOR THIRD LINE STAGE IV NON-SMALL CELL LUNG CANCER

SECTION THREE: Important Life Considerations

After learning they have a life-limiting illness, many people use this time to address a life review (what they have learned during life that they want to share with their families, and planning for events in the future like birthdays or weddings). It is very important to address these issues while you are still well.

1) **What resources are available to me (and my family) to address spiritual issues?**

The issues of living with cancer, and the possibility of dying from it, can shake the foundation of your life and its meaning. There is a safe place where you can share your fears, your emotions, and your struggle to find meaning, comfort, and hope.

A web resource has been created with the expert help of professional board-certified health care chaplains who are experienced in attending to the questions and concerns that you, as someone diagnosed with cancer or as a caregiver, are most likely dealing with. We understand that spirituality, religion, and beliefs are unique to each person and the information and resources here respect those differences.

www.cantbelieveihavecancer.org allows you to connect by email with a professional chaplain who is trained to listen and offer spiritual care to everyone regardless of religion or beliefs. There is also a phone support at 844-CHAPLAIN (844-242-7524).

CantBelieveIHaveCancer is a free service of HealthCare Chaplaincy Network, a national health care organization dedicated to helping people faced with the distress of illness and suffering find comfort and meaning. Learn more at www.healthcarechaplains.org

2) **What resources are available to me (and my family) to address financial issues?**

Sponsored by the American Cancer Society, this website has links to public and private resources that can help people with the cost of their medicines. Some of these programs have options for buying drugs at discounted prices. Others help people who cannot afford any part of their medicine costs.

<http://www.cancer.org/treatment/findingandpayingfortreatment/managinginsuranceissues/prescription-drug-assistance-programs>

Sponsored by the National Coalition for Cancer Survivorship, this "Cancer Survival Toolkit" includes helpful resources and information (in print and audio) about paying for cancer care. <http://www.canceradvocacy.org/resources/cancer-survival-toolbox/special-topics/finding-ways-to-pay-for-care/>

Sponsored by the Cancer Financial Assistance Coalition, this website features helpful information about financial assistance resources. <http://www.cancerfac.org/>

Fiduciary Organizations

Center for Guardianship Certification <http://www.guardianshipcert.org/>

Professional fiduciaries Association of California <http://www.pfac-pro.org/>

Public Guardians Association <http://www.capapgpc.org>

National Guardianship Association <http://www.guardianship.org>

National Academy of Elder Law Attorneys www.naela.org

Caregiver Action Network <http://www.caregiveraction.org/>

Family Caregiver Alliance <https://www.caregiver.org/>

3) What resources are available to me (and my family) to plan for future medical care?

People who suffer from a progressive disease can experience a sudden decline in health, leaving their family to question the extent to which treatment could help and under what circumstances the people would want it?

- 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, due to the cancer worsening, would you want to have resuscitation (CPR), or to be allowed to die naturally without resuscitation?

It's almost impossible to know what a person's medical wishes are unless the issue has been discussed ahead of time. The conversations you have today give your family and friends peace of mind when it comes to making decisions about your future healthcare. And the choices you document now give your healthcare team the ability to follow your directives in a medical crisis. Planning ahead lets everyone know what is important to you, and what is not – allowing them to devote more energy to compassionately following your wishes.

But to have your wishes respected you must first make them known.

Talking about death is not about giving up on life, it is a way to ensure greater quality of life, even when faced with a life-limiting illness. The resources below can help you plan ahead.

[Consumer's Toolkit for Health Care Advance Planning](#)

This toolkit contains a variety of self-help worksheets, suggestions, and resources, each clearly labeled and user-friendly. The guides help individuals discover, clarify, and communicate what is important to them in the face of serious illness. (The American Bar Association)

[Multi-State Power of Attorney for Health Care](#)

This simple form allows patients to appoint another person to make health care decisions if they become too ill or injured to communicate. (The American Bar Association)

[Prepare for Your Care](#)

The PREPARE website helps patients and their loved ones prepare for medical decisionmaking. Through videos and narration, people are encouraged to complete five steps that cover every aspect of advance care planning. The website is available in English and Spanish.

[Wise Conversations Planner](#)

This personal workbook includes practical worksheets to help individuals identify their medical, spiritual, and financial values, communicate their wishes to loved ones, and document their decisions. (DeathWise)

[Conversation Starter Kit](#)

Two kits help people talk with their families and doctors to develop a shared understanding of what matters most so that it is easier to make decisions when the time comes. Both kits are available in multiple languages. (The Conversation Project)

[Online Caregiver Resources](#)

This web portal offers a range of free materials for family caregivers, including information to help individuals and their loved ones get not only the best health care, but also the best quality of life. (Consumer Reports Health)

[Advance Care Planning Resources](#)

This comprehensive list of tools to help encourage people to talk to their loved ones now about their wishes for medical care and treatment in the event that they are unable to speak for themselves. (Coalition for Compassionate Care of California)

4) **What resources are available to me (and my family) to relieve the symptoms and address the stress of my illness?**

Palliative care, which helps relieve symptoms and address stress, is a very effective addition to standard cancer treatment for people with advanced non-small-cell lung cancer.

Palliative care alongside treatment (chemotherapy) is recommended by the American Society of Clinical Oncology and the National Comprehensive Cancer Centers Network.

- Palliative care is not the same as doing nothing;
- Taking advantage of palliative care does not mean giving up/abandoning hope;
- Palliative care may give you a higher quality of life and/or longer life;
- You do not need to be near death to benefit from palliative care;
- You do not need to stop treatment (chemotherapy) to benefit from palliative care;
- Palliative care is not the same as hospice

Palliative care is **specialized medical care** for people with serious illnesses.

This [video](#) from the American Lung Association explains what Palliative care is. This [toolkit](#), also from the American Lung Association, describes how palliative care can assist with treatment planning and other issues.

Palliative care is focused on providing patients with **relief from the symptoms, pain, and stress of a serious illness - whatever the diagnosis**. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors **to provide an extra layer of support**. Palliative care is appropriate at any age and at any stage in a serious illness, and **can be provided together with curative treatment**.

Palliative care can be provided by your oncologist in some cases, or by a special team working with your oncologist. For more information, and to find a palliative care team near you, go to <http://getpalliativecare.org/>

Additional Resources

National Cancer Institute <http://www.cancer.gov/cancertopics/advanced-cancer/care-choices/palliative-care-fact-sheet>

Cancer.net <http://www.cancer.net/navigating-cancer-care/how-cancer-treated/palliative-care/caring-symptoms-cancer-and-its-treatment>

American Academy of Hospice and Palliative Medicine <http://palliativedoctors.org/>
