

# patient decision aid advanced lung cancer

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## **Introduction**

This aid is meant to supplement conversations with your care team. Patients who have used a decision aid like this said it helped them make care choices that were best for them. This decision aid may help you as you make health care decisions. Use of this aid is voluntary.

## **What do you want to know?**

You will need to know certain things to make choices about what to do now and in the future. You should think about your values and needs to figure out what is most important to you. It can help to weigh the pros and cons of your treatment options. Some treatments may help improve your quality of life. Other treatments may increase the length of your life.

It can help to ask what your doctor, family, and friends think. It can help to think about what you want to know and how much you want to know. Think about how you would like things explained to you. Think about who is there to help you. The rest of this decision aid will help you sort through these things.

## **Information**

Some people want to know as much as they can about their situation, while others do not. You can choose how much and what kind of information you receive. You can choose to learn about your illness. You can choose to learn about your treatment options and the medicine used. You can choose to learn about possible side effects. You can choose to learn about your prognosis, which is a predicted outcome.

## **What do you need to know to make your decisions?**

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## **Communication**

What is the best way for you to learn about your situation? (select all that apply)

- I would like my doctor to explain
- I would like to read materials
- I would like to look at charts
- I would like to look at pictures

**Support**

Who else is involved? How can they support you?

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How can we help the people who support you?

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What role do you want in making your choices?

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

If you want help, from whom? (select all that apply)

- Doctor
- Spouse or Partner
- Children
- Other family member
- Other person \_\_\_\_\_

**What do you hope for?**

What is most important to you? Think about upcoming events, such as spending time with loved ones or doing favorite activities. Our goal is to help you enjoy these things for as long as possible.

Tell us about these special people, events and activities.

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*Thank you.* We appreciate you taking the time to help us understand what your needs and goals are so that we can provide you with the best care possible.

## Diagnosis

Your cancer started in your lung and has spread, or come back in another part of your body. Cancer is caused by cells that do not respond to normal signals in your body. These signals tell cells when to grow, stop growing, or to die. Instead, cancer cells continue to grow. They can spread to areas outside the lung. Once cancer has spread, it is called metastatic.

## Treatment

It is hard to know the outcome of treatment. Your outcome may be different from someone else's. We want to give you facts to help you make the decisions that are best for you. You may want to know how someone like you usually responds to treatment. You may want to know symptoms someone like you typically feels.

You can stop treatment or change to a different treatment. Some patients do this if the side effects are too difficult. There is no such thing as a wrong treatment choice. The choice that is best for you depends on what is most important to you.

You should understand the intent of your treatment. It is rare for metastatic cancer to be cured by treatment. "Cure" means to get rid of the cancer and not have it come back. Treatment may stop your cancer from growing or shrink your cancer. Yet, your cancer may continue to grow. This means that the intent of treatment is **not curative**. The purpose of treatment is **palliative**. This means that while we won't get rid of the cancer, we can improve the quality and length of your life.



## **Treatment Options**

You will need to decide what kind of treatment you want. There are three treatment options you can choose from for your stage and type of cancer.

1. Supportive care only
2. Anticancer treatment + supportive care
3. Non-treatment

### **1. Supportive Care Only**

Supportive care (also known as palliative care) gives you an extra layer of support. All patients with cancer are offered palliative care. Studies show that getting this care early helps patients feel better and live longer. This care addresses the emotional and social needs of you and your family. This may include needing help with pain, how you move around or the best way to eat to support your health. Palliative care can be given by your primary care team or by a specialist palliative care team.

### ***Supportive Care Treatments***

Supportive care services can give you relief from symptoms and side effects. You may not have the same symptoms as someone else. Common symptoms addressed include:

- fatigue
- loss of appetite
- constipation
- nausea
- shortness of breath
- depression
- anxiety
- pain

If you choose this option, you may need fewer clinical visits and tests. You may spend less time at the clinic or traveling to appointments. You may have fewer needle sticks for blood draws or IVs. This option means you would not get anticancer treatment, so you would not feel any side effects from that. This could be a relief when you may be feeling very tired. You may not live as long if you receive supportive care only. You may live longer if you get anticancer treatment and supportive care.

### ***Hospice***

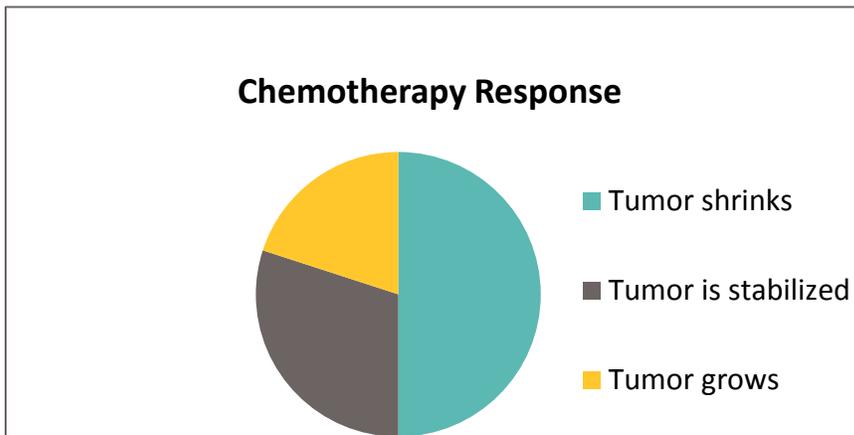
Hospice care is different from other supportive care because it is designed for people in the last six months of life. Hospice care is provided by nurses, social workers and other providers typically in your home. This can help you and your family feel as comfortable as possible. Your SCCA care team can continue to be involved in your care. Your doctor or a hospice consultant can give you more information about this option and whether it may be right for you.

## 2. Anticancer Treatment + Supportive Care

For initial treatment, the anticancer regimen of choice for your stage and type of cancer is a **chemotherapy** combination of **Carboplatin, Pemetrexed and Pembrolizumab**. Pembrolizumab is a type of treatment called immunotherapy. This medicine can help your own immune system fight your cancer. These three drugs are given by vein through an IV every three weeks. It's hard to tell how treatment will affect each person. This treatment option includes the support offered with palliative care, plus anticancer chemotherapy. When used with anticancer treatment, palliative care can help reduce symptoms of the cancer and side effects of treatment.

### ***Benefits of First Line Chemotherapy***

There is no way to know if chemotherapy would help you before treatment. For some people, it can extend their life and lower symptoms. To see if treatment is working, your doctors would look at CAT scans before and after two cycles of treatment. If the cancer has not grown, then the treatment is working. If the cancer continues to grow, then treatment is **not** working. Your doctors would check you for symptoms from cancer and side effects from treatment. They would also test your blood to make sure it is safe to continue treatment. After two cycles of chemotherapy:



About 50% patients have tumors that **shrink**.

About 30% patients have tumors that **don't grow, but they don't shrink**.

About 20% patients have tumors that will **grow**.

### ***Common Side Effects of Chemotherapy***

There are common side effects of chemotherapy that people feel, but how much or how often people feel these side effects is different from person to person.

Common side effects of this chemotherapy are:

- Fatigue - this usually is greatest for the week after chemotherapy.
- Nausea and vomiting – these are usually well-controlled with preventive treatments.
- Rash-this occurs in 10-15% of patients.
- Over time chemotherapy can cause anemia, which is a decrease in red blood cells. This can cause fatigue and may require blood transfusions.
- Low blood counts: chemotherapy can weaken the immune system. If you have fever (>100.4) you will need to call in for instructions and you may need antibiotics.

### ***Autoimmune Side Effects***

Immunotherapy can cause autoimmune side effects. If this happens, the immune system attacks healthy organs. This can affect the thyroid, lungs, liver, gut, skin and other organs. Serious side effects occur 5%-10% of the time.

### ***Other Side Effects***

Hair loss is not expected with this chemotherapy. There are many other potential, but less common side effects. It is important to tell your doctor about any unusual symptoms you may be having.

You can ask your doctor for more details about what your symptoms may be like and write about it here:

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### ***Supportive Medicines for Chemotherapy***

To reduce the side effects of chemotherapy, the following additional medicines are given:

- Dexamethasone-this medicine helps reduce nausea and prevents a rash from the chemotherapy
- Folic acid-this is a vitamin that reduces the effect of chemotherapy on blood counts
- Vitamin B12- this is a vitamin given as an injection to reduce the effect of chemotherapy on blood counts
- Palonsetron-this is an anti-nausea medication given by vein through an IV

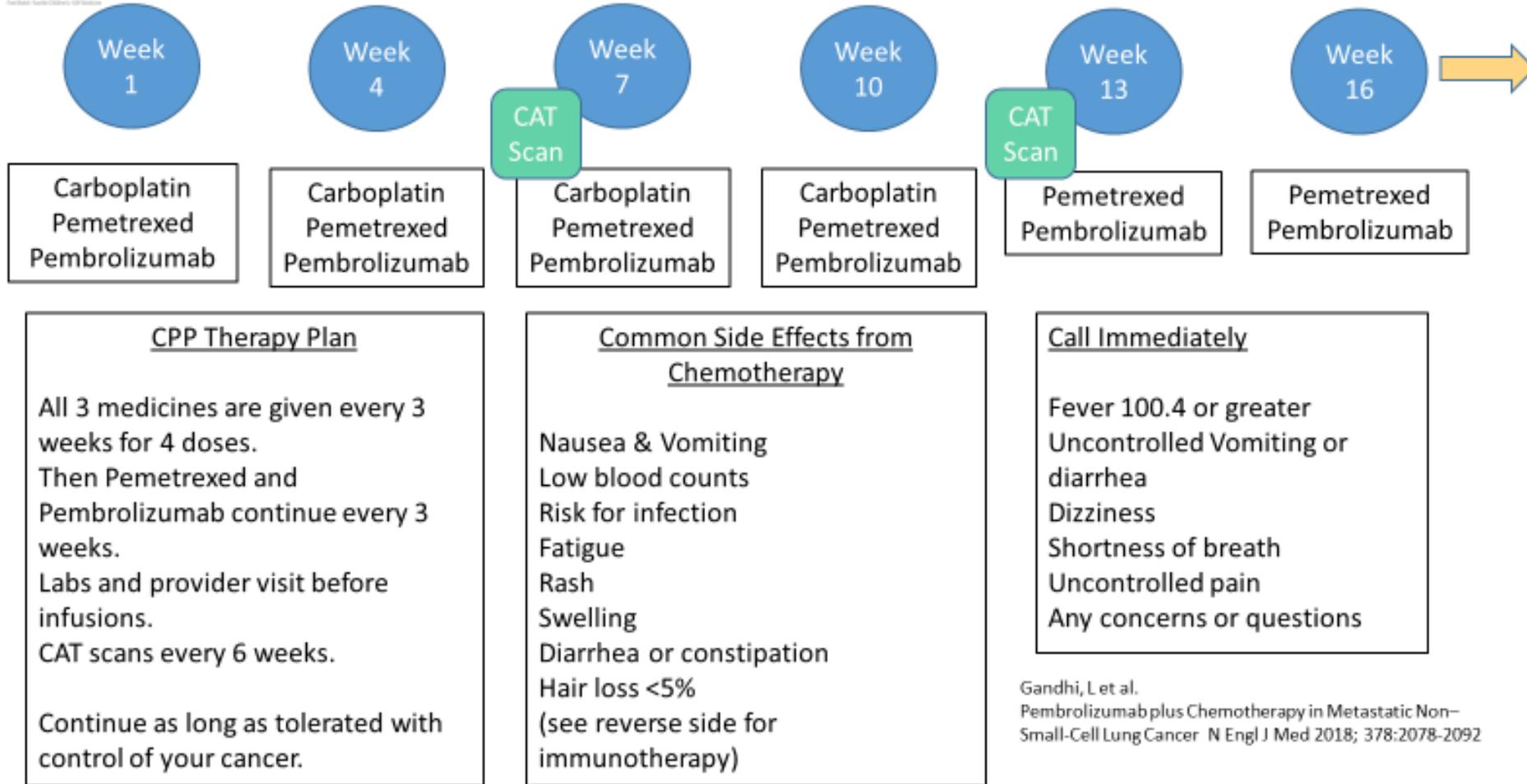
### **3. Non-Treatment**

You may not want any treatment that is offered, and that is your choice too. You can choose to decline all treatment offered, which means you do **not** come back for care. You can change your mind at any time to receive treatment or discontinue treatment. The choice is yours and we will be here to help you no matter which choice you make.

**There is more information about Anticancer Treatment + Supportive Care on page 7.**

**There is an overview of your treatment options on page 8.**

## Carboplatin Pemetrexed and Pembrolizumab (CPP) for Non-Small Cell Lung Cancer



## Overview of Treatment Options

	Non-Treatment	Hospice	Supportive Care Only	Supportive Care + Anticancer Treatment
Will my pain and cancer symptoms be treated?	No, you will have chosen not to come back for care	Yes	Yes	Yes
Will I be offered interpersonal and spiritual support?	No, you will have chosen not to come back for care	Yes	Yes	Yes
Will I receive chemotherapy?	No, you will have chosen not to come back for care	No	No	Yes
Will I be offered radiation or minor surgery if it could relieve my cancer symptoms?	No, you will have chosen not to come back for care	No	Yes	Yes
How often will I need to come in to the hospital or clinic?	Never	Only if comfort measures can't be given at home	About once every 1 to 3 months and when you have problems	Can vary. Sometimes as often as weekly, but typically every 3 weeks.
			<i>Plus possible extra visits for tests</i>	
How often will I need blood tests?	Never	Never	This varies. If you have symptoms suggesting a blood abnormality, and for some doctors, at each visit (every 1 to 3 months)	Before treatments or if you have symptoms suggesting abnormal blood tests
How often will I need x-rays or CAT scans?	Never	Never	The need for scans is driven by symptoms	Every 2 or 3 months to assess if the treatment is working



### Weighing the pros and cons of your treatment options

Your choice is whether to receive supportive care only, supportive care + anticancer chemotherapy or no treatment.

This exercise gives examples of the pros and cons of each option. Take a few minutes and add any pros or cons that are important to you.

Which pros and cons matter to you most?

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Pros of supportive care only	Pros anticancer treatment + supportive care	Pros of no treatment
<ul style="list-style-type: none"><li>-fewer blood tests and needle sticks</li><li>-fewer appointments</li><li>-more time for family and loved ones</li></ul>	<ul style="list-style-type: none"><li>-I may live longer</li><li>-May reduce my symptoms from cancer</li><li>-May reduce the side effects of treatment</li></ul>	<ul style="list-style-type: none"><li>-No chemotherapy side effects</li><li>-No time spent at clinic</li><li>-I can be at home more</li></ul>
Cons of supportive care alone	Cons anticancer treatment + supportive care	Cons of no treatment
<ul style="list-style-type: none"><li>-I may not live as long</li><li>-Need trips to clinic or hospital</li></ul>	<ul style="list-style-type: none"><li>-May cause side effects from treatment</li><li>-More time spent in clinic</li><li>-More time spent traveling to appointments</li></ul>	<ul style="list-style-type: none"><li>-I may not live as long</li><li>-My symptoms may not be well managed</li></ul>

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**Are you leaning towards no treatment, supportive care alone or adding anticancer treatment?**

(check a box to tell us where you are leaning)

No Treatment-----Supportive Care Only-----Anticancer Treatment +  
Supportive care

**What other questions do you have for your doctor?**

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