

You just learned that you have advanced or metastatic lung cancer. You may be hearing about lung cancer for the first time or this may be a recurrence of a previously treated lung cancer. Either way, you have a lot to process, and you may have decisions to make.

The past few years have been an exciting time for lung cancer research. New drugs bring new hope but there are still unanswered questions.

This fact sheet provides an overview of treatment for metastatic lung cancer. It is designed to help you learn more about your options, know what questions to ask and start to feel empowered to take control of your cancer and your life.



**CANCER SUPPORT
COMMUNITY.**

A Global Network of Education and Hope

SOURCES FOR INFORMATION ABOUT METASTATIC LUNG CANCER

Cancer Support Community 888-793-9355 www.CancerSupportCommunity.org

Free to Breathe 844-835-4325 www.freetobreathe.org

Lung Cancer Alliance 800-298-2436 www.lungcanceralliance.org

LUNgevity Foundation 312-407-6100 www.LUNgevity.org

Metastatic Lung Cancer

Cancer occurs when abnormal cells grow, multiply and form tumors. Cancer cells can invade and destroy healthy tissue and spread to other parts of the body. This process is called metastasis. Cancer that has spread is metastatic, but even if lung cancer spreads to the liver or bones or other sites, it is still lung cancer and is treated with lung cancer treatments (not those for liver or bone cancer, for example). Metastatic cancer is sometimes called advanced or extensive stage cancer or Stage IV.

Many people with lung cancer do not notice symptoms until the cancer has spread. Most often the symptoms come from the metastasis rather than the original site of the tumor. As a result, lung cancer is often metastatic when it is diagnosed.

There are two main types of lung cancer. They differ in how the cancer cells look under a microscope, how they behave and how they respond to different treatments.

- Non-small cell lung cancer (NSCLC) accounts for 85% of all lung cancers. Its main subtypes are adenocarcinoma, squamous cell carcinoma and large cell carcinoma.

- Small cell lung cancer (SCLC) accounts for 15% of lung cancers. It is mostly seen in current or former smokers.

Making Treatment Decisions

Over the coming days or weeks, you may hear about possible treatments and be asked to make decisions. Some of the information may be hard to hear, and these conversations might feel overwhelming at times.

The way doctors treat cancer has been changing quickly. Biomarker tests can help determine if a new treatment like targeted therapy or immunotherapy might work for you, or if chemotherapy is a better choice. Ask to have your tumor genetically tested for at least the markers called EGFR, ALK, ROS, and BRAF, and also tested for PDL1 protein expression. Ask what these results mean for you.

REMEMBER TO:

- Ask questions until you understand what you are being told. Learn about the different treatments and why one might work better for you than another.
- Talk with family, friends and your health care team as you consider your next steps.
- Seek support.
- Lung cancer diagnosis and therapy have become very complicated and are rapidly changing. Consider getting a second opinion from a lung cancer specialist rather than a doctor who treats all kinds of cancer. Talking with a second doctor can help you better understand your disease and how to treat it.
- Use the discussion tool on the next two pages. Review it before each visit to help you decide the most important questions to ask your health care team.

WANT MORE HELP TALKING TO YOUR HEALTH CARE TEAM?

If you are facing a cancer treatment decision, Cancer Support Community's Open to Options® research-proven program can help you prepare a list of personalized questions to share with your doctor. Our Open to Options specialists can help you create a written list of specific questions about your concerns for your doctor. Call 1-888-793-9355 to schedule an appointment or to find a Cancer Support Community near you.



Talking with Your Health Care Team About Metastatic Lung Cancer Treatment

There has been a lot of progress in the treatment of metastatic lung cancer in recent years. New treatments are helping more people live longer or more comfortably. You may be given choices that you would not have had just a few years ago. This worksheet can help you talk with your health care team about your treatment options.

CHOOSING A DOCTOR OR HOSPITAL

Metastatic lung cancer can be hard to treat and several new treatments have been approved in the past few years. You want an experienced, multidisciplinary oncology team who specializes in lung cancer. Try to find a medical oncologist who mostly treats lung cancer. If you need a surgeon, look for one who is “board-certified” in thoracic surgery. If this is not possible, find the surgeon who does the most lung cancer surgeries in your area. You are more likely to find these doctors in a major medical center, teaching hospital or a National Cancer Institute-designated cancer center (www.cancer.gov/cancer-centers).

KNOW THE FEATURES OF YOUR LUNG CANCER

This means the type, the stage (how advanced it is) and what your doctor may have learned about your cancer’s genetic profile.

ASK THESE QUESTIONS

Do I have small cell lung cancer or non-small cell lung cancer? If non-small cell, what kind? _____

What stage is my cancer? _____

If my tumor is an adenocarcinoma, what are the genetic analysis results for the cancer’s EGFR, ALK, ROS, RET, and BRAF genes? _____

Does my cancer express PD-L1? What does that mean for my treatment? _____

GET THE MOST OUT OF YOUR VISIT WITH YOUR HEALTH CARE TEAM.

- Ask questions. Write down your questions before each health care visit.
- Take someone with you to appointments, for support and an extra set of eyes and ears. Take notes or ask your friend or relative to take notes for you, or record the visit.
- Tell your health care team about any symptoms, side effects or concerns you have.
- Ask about clinical trials.

QUESTIONS TO ASK YOUR HEALTH CARE TEAM

- What treatment do you recommend?
- Are there other treatments that might work for me?
- Are there any clinical trials that are right for me?
- Are there other resources that can help me during this time?
- What treatments are available when this one stops working?

FOR EVERY TREATMENT YOU DISCUSS WITH YOUR DOCTOR OR OTHER HEALTH CARE TEAM MEMBERS:

- Why do you recommend this treatment?
- What is the goal of this treatment?
- Why is this treatment a good choice for me? How likely is it to work?
- Is there a lab test that I can have to help determine if this treatment will work for me? If yes, has this test been run? What were the results?
- How often will I need to go to your office or the hospital for this treatment? Will I need to stay overnight?
- What side effects might I expect and how can I prepare for them?
- How do you treat these side effects?
- How will you know if the treatment is working?
- Should I be considering palliative therapy/supportive care?
- How much does this treatment cost? Is it covered by my insurance?

OTHER THINGS YOUR HEALTH CARE TEAM SHOULD KNOW

As you think about treatment, ask yourself these questions, or talk about them with a loved one or trusted counselor. Once you know the answers to these, let your health care team know your goals, what is important to you and what you are worried about. This will help them provide the care you need.

- What are my goals for my treatment?
- What is most important to me right now?
- What am I worried about?

WHILE YOU ARE IN TREATMENT, BE SURE TO DISCUSS THE FOLLOWING WITH YOUR DOCTOR OR OTHER HEALTH CARE TEAM MEMBERS:

- Tell them about any side effects you might be having, and whether they are getting better or worse
- Tell them if you have pain anywhere and if so, how you have been managing it.
- Tell them if you are having difficulty doing regular activities of daily living (dressing, eating, sleeping).
- When will we know if the treatment is working? What do we do next if it isn't?

TALKING ABOUT CANCER

Cancer talk can sound like a different language. The words below may be used during treatment planning. Refer to CSC's Frankly Speaking About Lung Cancer book (www.CancerSupportCommunity.org/LungBook) for a more complete list of lung cancer vocabulary.

FIRST-LINE THERAPY: The initial cancer treatment. Second-line therapy may follow if the first line is not successful or stops working, and so on.

BIOMARKER: A biological marker found in cells or tissues that is a sign of a normal or abnormal process, or of a condition or disease.

BIOMARKER TESTING (ALSO KNOWN AS MOLECULAR TESTING):

Uses samples of a person's cancer. The samples are taken by a biopsy or surgery. A biomarker test looks at the cancer's unique biological makeup. This information can be used to help choose treatments for a person's specific lung cancer.

BIOPSY: Surgical removal of a small piece of tissue for evaluation under a microscope.

GENETIC PROFILING TESTS: are a specific kind of biomarker testing that should be used to determine whether your cancer is likely to respond to EGFR, ALK, ROS and BRAF targeted therapy. These tests are done on the cancer's genes and do not mean your lung cancer was "inherited."

MAINTENANCE THERAPY: Lower intensity therapy given after first-line therapy to delay the return of cancer.

METASTASIS: The spread of cancer to other tissues.

MULTIMODALITY OR COMBINED MODALITY THERAPY:

Treatment using a combination of chemotherapy, surgery, radiation therapy, immunotherapy and/or targeted therapy.

Treatment Options

Treatment for both small cell and non-small cell lung cancer involves one or more of the following approaches.

Surgery is the preferred treatment for lung cancer if it is caught before it has spread outside the lung (about 20% of cases). Chemotherapy, targeted therapy or immunotherapy (with or without radiation) is a standard treatment for all other lung cancers.

Chemotherapy

Chemotherapy works by killing cancer cells so they cannot divide, multiply, and spread. This helps ease symptoms and may help some people live longer.

You may be given one drug or a combination of drugs, usually through a vein. Because the drugs work for days or weeks after they are taken, a period of rest and recovery follows each dose or cycle.

Chemotherapy drugs commonly used to treat lung cancer include:

- Carboplatin (Paraplat[®] or Paraplatin[®])
- Cisplatin (Platinol[®]-AQ or Platinol[®])
- Docetaxel (Taxotere[®])
- Etoposide (Toposar[®] or VePesid[®])
- Gemcitabine Hydrochloride (Gemzar[®])
with cisplatin (Platinol-AQ[®] or Platinol[®])
- Paclitaxel (Taxol[®]), in combination with
Cisplatin (Platinol[®]-AQ or Platinol[®])
- Paclitaxel Albumin-stabilized Nanoparticle
Formulation (Abraxane[®] - also called
Albumin-bound Paclitaxel or Nab-paclitaxel)
in combination with Carboplatin
- Pemetrexed Disodium (Alimta[®])
- Topotecan Hydrochloride (Hycamtin[®])
- Vinorelbine Tartrate (Navelbine[®])

SIDE EFFECTS OF CHEMOTHERAPY

Everyone reacts differently to chemotherapy. Some people have virtually no side effects, and others have

many. Common side effects include fatigue, diarrhea, constipation, nausea and vomiting, hair loss, skin problems, numbness and tingling, hearing loss and low blood cell counts. It is important to tell your doctor about your side effects. Your doctor may alter the chemotherapy, adjust the dose or give you other medications to help. It is also common to experience forgetfulness, confusion or have difficulty remembering words while taking chemotherapy. Tell your doctor about these symptoms.

Immunotherapy

Immunotherapy works by boosting the body's natural ability to fight cancer. In order to become a cancer, the cell must have figured out how to avoid being killed by the immune system. Scientists have figured out some of the ways cancers do this. Scientists are using this knowledge to develop immunotherapy drugs to help the immune system work better. Some of these are now FDA approved and many more are being studied in clinical trials. Talk with your doctor about whether these drugs might be an option for you and why. Refer to CSC's *Your Immune System and Lung Cancer* fact sheet (www.CancerSupportCommunity.org/IOLung) for more information on how immunotherapy works. Major approaches, and the drugs used, include:

CHECKPOINT INHIBITORS The immune system has safeguards in place to prevent it from attacking healthy cells. These safeguards are called checkpoints. They slow down or stop an immune attack when healthy tissue is threatened. Some cancers have learned how to activate these checkpoints to avoid being killed by the immune system. New drugs aim to deactivate the checkpoint, helping the body fight cancer. Three major checkpoints are being targeted in lung cancer: the PD-1, PD-L1 and CTLA-4 proteins. Drugs that target them are now approved in certain situations, but there is still a lot to learn. Expression of PD-L1 is associated with benefit from PD-1- and PDL-1-targeted therapies.

Immunotherapy drugs used to treat lung cancer include:

- Nivolumab (Opdivo®)—Anti-PD-1
- Pembrolizumab (Keytruda®)—Anti-PD-1

Ipilimumab (Yervoy®) is an anti-CTLA-4 approved in melanoma but under study in lung cancer.

IMMUNOTHERAPY APPROACHES STILL BEING STUDIED

CANCER VACCINES: Vaccines attempt to induce immune responses to tumor antigens. Antigens are characteristics of cancer cells that mark them as abnormal. Many attempts have been made to do this in the past, and none of them have been successful to date, but new combinations may hold promise. Clinical trials for lung cancer are testing whether vaccines can delay or prevent recurrence or treat advanced disease.

ADOPTIVE T CELL THERAPY: T cells are the immune system’s fighters. This experimental treatment removes a person’s T cells, alters them to make them stronger and better able to fight cancer then returns them to the body to go to work. T cell therapy is available through clinical trials at a limited number of medical centers.

COMBINATION THERAPIES: Studies are ongoing to see if immunotherapies can be used in combination with each other or with other treatments like chemotherapy.

SIDE EFFECTS OF IMMUNOTHERAPY

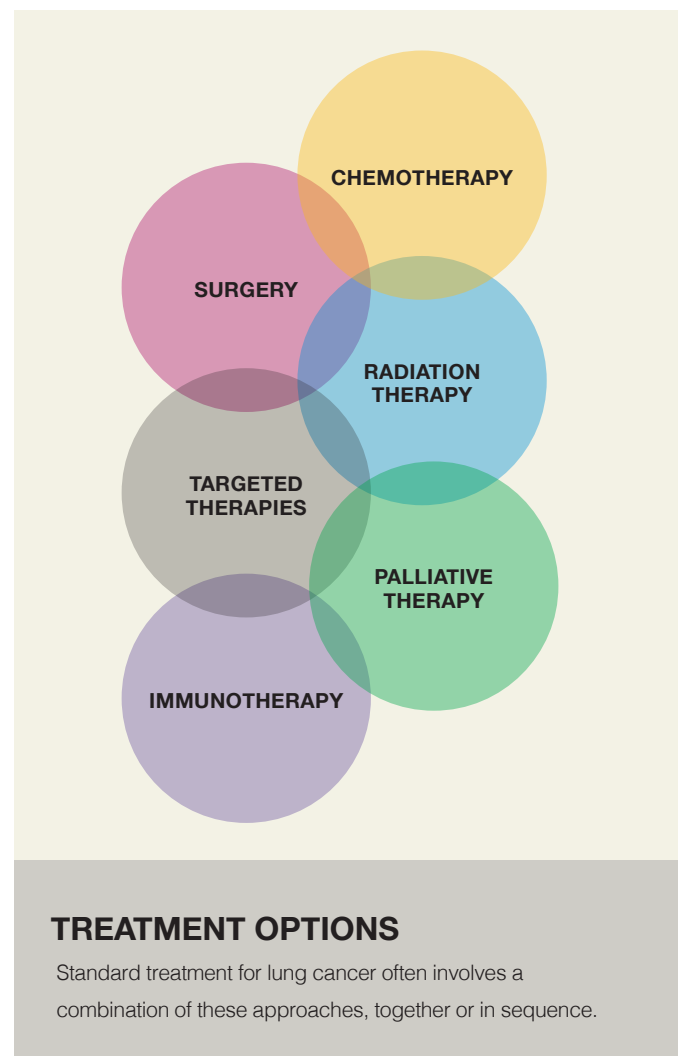
Immunotherapy works differently from other forms of cancer treatment. It can take weeks to see positive results. Tumors may seem to grow before they begin to shrink.

The side effects also vary significantly. They are usually mild, but range from mild to severe. Common ones include fatigue, fever, itching, diarrhea and skin rashes. The more serious ones are autoimmune disorders that affect hormone levels or major organs. It is very important to tell your health care team right away about any changes you notice. Side effects are best treated when diagnosed early.

Targeted Therapy

Targeted therapy treats cancer at its most basic biological level. Researchers study tumor cells to find genetic alterations in tumors that may “drive” cancer growth. They then develop “targeted” drugs to inhibit or block these drivers. Clinical trials have shown remarkable responses when certain drivers are treated with specific drugs to block them. Many genetic biomarkers have been associated with lung cancer, and more may be discovered in the coming years. Most biomarkers have been found in the subset of non-squamous non-small cell lung cancer.

These drugs are not for everyone. Genetic analysis of your tumor can tell your doctor if your cancer might respond to a targeted drug. Ask to have your tumor tested for genetic markers, especially EGFR, ALK, ROS, and BRAF.



Targeted therapies often work well initially. Over time, however, they usually stop working and the cancer starts to grow again. Refer to CSC's *Advances in Lung Cancer* fact sheet (www.CancerSupportCommunity.org/TargetedLung) for more information on targeted therapies and biomarkers.

■ **These drugs target the biomarker EGFR:** Erlotinib (Tarceva®); Afatinib (Gilotrif®); Gefitinib (Iressa®); Osimertinib (Tagrisso™)

■ **These target ALK:** Crizotinib (Xalkori®); Ceritinib (Zykadia™); Alectinib (Alecensa®).

The drugs listed above are in pill form and can be taken at home.

Another class of “targeted” therapy drugs are antibodies that are given by vein. They do not seem to work as well and do not currently have a good biomarker for who benefits and who does not, but are sometimes used. They include:

■ Bevacizumab (Avastin®) an antibody targeting VEGF

■ Ramucirumab (Cyramza®) an antibody targeting VEGF

■ Necitumumab (Portrazza™) an antibody targeting EGFR

Other biomarkers relevant to lung cancer that may guide targeted therapies include HER2, MET, MEK1, Trk, and RET. Ask if your tumor has been tested for these biomarkers and if so, are there any additional treatment options or clinical trials you should consider.

SIDE EFFECTS OF TARGETED THERAPY

Targeted therapies have fewer side effects than other cancer treatments. Skin rash is a very common side effect but doesn't occur at all in some people. Ask about it before you start treatment so that you can have medicine available if needed. Rashes often get better with time. Other side effects can include: changes in hair growth or color, mouth sores, breathing problems, diarrhea, nausea and vomiting, fatigue and headache.

Bevacizumab (Avastin®) and Ramucirumab (Cyramza®) may cause high blood pressure, bleeding, wounds that will not heal and tears in the stomach or bowel wall.

LLOYD understands the importance of participating in a support group. After being diagnosed with lung cancer he sought support from his local Cancer Support Community. Lloyd recalls, “Emotional support is not at the top of the list for us guys, but it is so important. There are a lot of men out there who need emotional support. I now meet with a group of men with different kinds of cancer; we eat and discuss how we are doing with our illness.”

In addition to attending support groups, Lloyd also practices mindful meditation, which has helped him live more in the present moment. “One thing I've learned from my cancer journey is to simply slow down. Reduce the amount of anxiety and deal with any mental issues I am experiencing. The biggest thing that has helped me is mindfulness programs. I was simply shown another way that I can effectively reduce my stress and anxiety to a point where it is nicely manageable.”



Radiation Therapy

Radiation therapy uses high-powered energy beams such as x-ray, to treat cancer and its symptoms. It can help relieve pain and improve quality of life in people with advanced lung cancer. The rays are similar to those used in a chest x-ray but much stronger. The most common type of radiation therapy used for lung cancer is external-beam radiation therapy. This can be given as one or a few very high focused doses (radiosurgery) or in lower doses given over a longer period of time (fractionated radiation). This painless procedure lasts only a few minutes but the setup takes longer.

SIDE EFFECTS OF RADIATION THERAPY

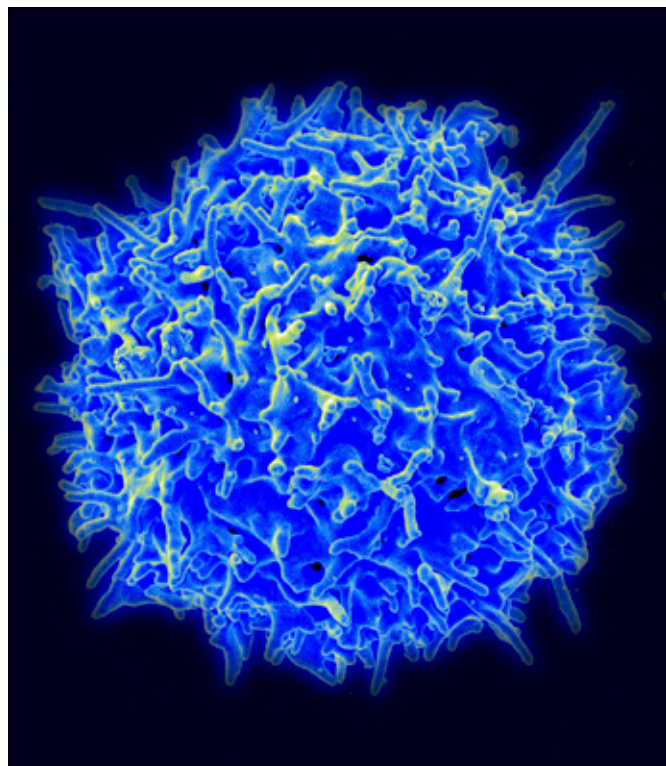
Common side effects include fatigue, hair loss in the area radiated, difficulty swallowing (for radiation to the chest), sunburn-type skin problems and low blood cell counts.

Surgery

Surgery is an operation to physically remove a tumor. It is the best treatment for early-stage lung cancer which has not spread outside the lung, if you are strong enough to tolerate it and it can be done. Surgery is rarely (but occasionally) an option for metastatic lung cancer. When it is, it can involve removal of all or part of a lung.

SIDE EFFECTS OF SURGERY

Lung surgery can cause pain and discomfort and breathing problems. These are lessened with “minimally invasive” approaches using robotics or video-assisted techniques. It also brings general risks such as reaction to anesthesia, bleeding, blood clots and infections. Doctors sometimes recommend pulmonary rehabilitation or inhalers to help with breathing before or after surgery.



LUNG CANCER CELL

Palliative Therapy

The best way to treat cancer pain and symptoms is to effectively treat the cancer. Palliative therapy (also called supportive care) is used to manage your symptoms while other therapies are used to treat the cancer. The goal of palliative therapy is to help you feel more comfortable. Let your health care team know if any medication you are given adds to your discomfort. Ask if there is someone on their team who specializes in palliative care.

Side Effects of Treatment

Even when your cancer therapy is working to kill the cancer, cancer treatment can give you new symptoms. Coping with the side effects of treatment can be one of the hardest parts of cancer. It helps to plan in advance and talk with your health care team.

BEFORE YOU START TREATMENT: Ask your health care team about the side effects of the treatments you are considering. Find out how to manage them.

AFTER YOU START TREATMENT: Keep track of how you feel. Write down when you notice a problem, how long it lasts and if there is anything that makes it better. Let your health care team know what you are experiencing so they can help you feel better and prevent more serious problems from developing.

Keep in mind that you cannot tell how well a treatment is working by the number or intensity of side effects. Everyone experiences side effects differently. Refer to CSC's *Frankly Speaking About Lung Cancer* book (www.CancerSupportCommunity.org/LungBook) for more information.

ARE THERE OTHER TREATMENTS THAT MAY WORK?

You may hear of special diets or other treatments from family, friends or the media. Many of these are not based in science. Some can be very costly, and even cause harm or can interfere with treatment. Talk with your health care team about anything you are doing or considering doing to help with lung cancer or the side effects of treatment.

Clinical Trials

As you consider your options, be sure to ask about clinical trials. Clinical trials are research studies to test new treatments or learn how to use existing treatments in different ways. Today's newest treatments were studied in yesterday's clinical trials. Today's clinical trials may become tomorrow's newest treatments. Key things to know:

- A clinical trial may be the only way to get certain treatments, including some that are very promising.
- The U.S. Food and Drug Administration and numerous ethical review processes oversee all U.S. clinical trials to keep patients safe.
- If you join a clinical trial, you can leave at any time.
- Every doctor does not have the same trials.
- Trials are available for different stages and types of lung cancer, although everyone is not eligible for every trial.

■ Most often, the costs of the drug are paid for by the trial, with only "standard" procedures paid by you or your health insurance. However, your health insurance may not pay for everything. Be sure to ask.

Lifestyle and Support

Learning you have lung cancer is not easy. You have a lot of information and feelings to process. You also may have practical concerns about work or health insurance. Be sure to take care of yourself and ask for help. More information on the lung cancer experience, coping and practical concerns can be found in CSC's *Frankly Speaking About Lung Cancer* book (www.CancerSupportCommunity.org/LungBook).

LEARN MORE ABOUT CLINICAL TRIALS

Cancer Support Community
888-793-9355
www.CancerSupportCommunity.org/clinicaltrials

Lung Cancer Alliance
Clinical Trial Matching Service
800-698-0931
www.LungCancerAlliance.org/clinicaltrials

LUNGeVity Foundation
Clinical Trial Matching Service
800-698-0931
LUNGeVity Foundation Clinical Trial Finder
www.ClinicalTrials.lungevity.org

National Cancer Institute
800-422-6237
trials.cancer.gov

National Library of Medicine's
Clinical Trial Search
www.ClinicalTrials.gov

Lung Cancer Information, Survivorship & Support

American Cancer Society 800-227-2345 www.cancer.org

Bonnie J. Addario Lung Cancer Foundation www.lungcancerfoundation.org

CancerCare 800-813-4673 www.cancercare.org

Cancer.net 888-651-3038 www.cancer.net

Free to Breathe 844-835-4325 www.freetobreathe.org

LUNGevity Foundation 321-407-6100 www.LUNGevity.org

Lung Cancer Alliance 800-298-2436 www.lungcanceralliance.org

National Cancer Institute 800-422-6237 www.cancer.gov

Patient Advocate Foundation 800-532-5274 www.patientadvocate.org

CANCER SUPPORT COMMUNITY RESOURCES

The Cancer Support Community's (CSC) resources and programs are available free of charge. To access any of these resources below call 888-793-9355 or visit www.CancerSupportCommunity.org

CANCER SUPPORT HELPLINE ®

Whether you are newly diagnosed with cancer, a long-time cancer survivor, caring for someone with cancer, or a health care professional looking for resources, CSC's toll-free Cancer Support Helpline (888-793-9355) is staffed by licensed CSC Helpline Counselors available to assist you Mon-Fri 9am - 9pm ET.

OPEN TO OPTIONS ®

If you are facing a cancer treatment decision, this research-proven program can help you. In less than an hour, our trained specialists can help you create a written list of specific questions about your concerns for your doctor. Appointments can be made by calling 888-793-9355, visiting www.CancerSupportCommunity.org or by contacting an Affiliate providing this service.

CANCER EXPERIENCE REGISTRY ®

The Registry is a community of people touched by cancer. The primary focus of the Registry is on collecting, analyzing and sharing information about the experience and needs of patients and their families. To join, go to www.CancerExperienceRegistry.org.

FRANKLY SPEAKING ABOUT CANCER ®

CSC's landmark cancer education series provides trusted information for cancer patients and their loved ones. Information is available through publications, online, and in-person programs.

AFFILIATE NETWORK SERVICES

More than 50 locations plus 120 satellite locations around the country offer on-site support groups, educational workshops, and healthy lifestyle programs specifically designed for people affected by cancer at no cost to the member.

THE LIVING ROOM, ONLINE

Here you will find support and connection with others on discussion boards, a special space for teens, and personal web pages to keep your family and friends up-to-date.

FRANKLY SPEAKING ABOUT CANCER: TREATMENT FOR METASTATIC LUNG CANCER PROGRAM PARTNER



Cancer Support Community and its partners provide this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professionals to answer questions and learn more.

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