

THE
Educated Patient[®]

Non-Small Cell Lung Cancer

RESOURCE GUIDE



Presented by

cure[®]

A collection of resources that provide information and support for patients and the professionals who treat them

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Tabitha Paccione and her family.

Non-Small Cell Lung Cancer: One Survivor's Story

A Patient's Perspective on Diagnosis and Treatment

HI, MY NAME IS TABITHA PACCIONE, and in September 2016 I was diagnosed with stage 4 lung cancer. One of my early symptoms was a cough, which I initially thought was due to a respiratory illness. I was teaching first-graders and would get sick every year. The coughing got worse, so I went to my primary care doctor and got some antibiotics and cough medicines. The doctor did a chest X-ray, which came back clear. But the cough just would not go away, so I went back. She said it might have been allergies or perhaps acid reflux. I didn't feel that it was acid reflux, so I requested a second opinion. Around this time, I was experiencing back pain and asked my doctor about it. She figured I must have pulled a muscle because I had been working out a lot, and she gave me some muscle relaxers.

In terms of other symptoms, I never coughed up blood; it was always just clear phlegm. I was exhausted all the time and short of breath. One evening when I was out on a date with my husband, we were at a movie theater. As we were going down four steps, I grabbed his arm and asked him to slow down because I needed to catch my breath. I remember telling him, "There's something wrong with me!"

I got a few different opinions. One doctor wanted to run a CT scan and an MRI because I hadn't had those yet. The CT scan showed a five centimeter tumor in my left lung. I was just 35 and had never even tried cigarettes. No one suspected lung cancer. I had a lung biopsy, which confirmed that I had adenocarcinoma.

I also had a PET scan, and that's when I found out I was stage 4 — the cancer was in my brain, liver, lymph nodes and bones.

The doctor sent a blood sample and the tissue from the biopsy for comprehensive biomarker testing, which took three weeks. My cancer was growing very quickly, so while we were waiting, I had one cycle of chemotherapy. Once my biomarker testing results were back, my doctor switched me to targeted therapy.

Treatment has given me more time with my kids. The coughing went away, I can breathe and I have energy again. This can be different for everyone, but for me, with the targeted therapy, the side effects are minimal. I've also had a chance to get involved with advocacy. Now I get to tell my story and hopefully help others and encourage them to fight.

My advice to others on this journey is to live your very best life. Live like every day is your last. Be kind to people and take chances. Be positive and don't sweat the small stuff. Share your journey with others and allow people to help you. Lung cancer can be scary, but there are so many treatments available today and more research is being done. You can do this. You can live a quality, long life with the support of family, friends and your medical team. Fight and fight hard — realize who you are fighting for and fight. Don't give up. You can do it!

—TABITHA PACCIONE

About Non-Small Cell Lung Cancer

IN THE UNITED STATES, an estimated 228,820 people were diagnosed with lung cancer in 2020.¹ About 80% to 85% of people with lung cancer have non-small cell lung cancer (NSCLC). Signs or symptoms of NSCLC may include difficulty breathing, a cough that doesn't go away, wheezing or coughing up blood; however, some patients do not experience any signs or symptoms.²

NSCLC is categorized into subtypes based on what cells in the lungs it affects. The most common subtypes are adenocarcinoma, squamous cell carcinoma and large cell carcinoma.³

Adenocarcinoma is usually located in the outer parts of the lung. It begins in cells that create mucus and other substances. Squamous cell carcinoma, which is typically found in the middle of the lungs in cells lining the inside of the airways, is the subtype most often caused by smoking.³ Recently, it has been diagnosed less frequently.¹ Large cell carcinoma can be harder to treat than the other subtypes because it usually spreads quickly. This subtype can grow from anywhere in the lung.³

The biggest factor that increases the chances of developing NSCLC is smoking. Other factors include exposure to secondhand smoke; air pollution; certain sources of radiation; and some chemicals and heavy metals, such as asbestos, arsenic and chromium. The chance of getting NSCLC increases with age and having a family history of lung cancer.²

Diagnosing NSCLC

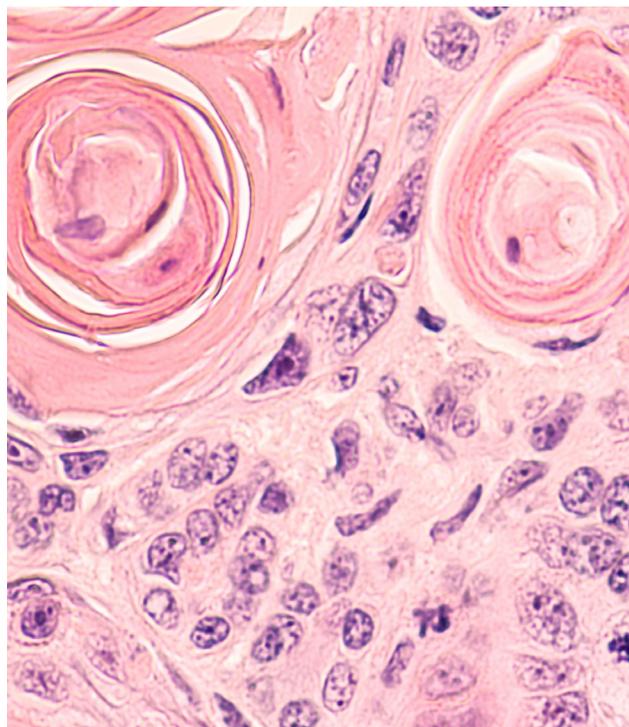
Various tests and procedures may be used to detect and diagnose NSCLC. If your doctor suspects NSCLC, he or she will likely review your medical history and conduct a physical examination. Your doctor may also recommend one or more of the following tests^{2,4}:

- **Chest X-ray:** Takes pictures of the bones and organs with beams of energy; often used as an initial test to check for areas in the lungs that look abnormal.
- **CT scan:** Combines many X-rays into a detailed image that can show specifics about tumors (such as size, shape and placement in the lung) and can identify other areas in the body where the cancer might have spread.
- **MRI scan:** Uses radio waves and magnets to show the details of a tumor. May be used to determine whether the cancer has spread to areas outside the lungs, such as the brain or the spinal cord.

- **PET scan:** Involves injection of a tracer into the bloodstream that helps identify certain areas more clearly. PET scans can be used in combination with CT scans to look for places where the cancer may have spread.
- **Biopsy:** Involves inserting a hollow needle into the body to draw a sample of tissue for testing; a CT scan is often used to guide the needle. The cells are then examined under a microscope and may also be sent for additional testing. This can help your doctor confirm a diagnosis of NSCLC and determine which drugs could offer the best treatment.

Staging NSCLC

The stage of NSCLC describes whether the cancer has spread and how far. The system most frequently used to stage cancer is the TNM system, which describes the tumor (T) and whether it has spread to lymph nodes (N) or other areas of the body through metastasis (M). With measurements across these three categories, your doctor can stage NSCLC from 0, the earliest stage, through 4, the most advanced stage. The letters A, B and C can be assigned to show advancements within each stage (for example, stages 3A, 3B and 3C).⁵



Stages 3 and 4 NSCLC describe phases in which there is greater cancer spread outside the lungs. With stage 3, the cancer has grown into nearby lymph nodes, structures or organs, such as the chest wall, the heart, the windpipe, the esophagus (the tube connecting the throat to the stomach) and the spine.⁵

Stage 4 describes spread to distant parts of the body (metastasis). With this stage, the original lung tumor could be any size, could have grown into any nearby structure and could have reached local lymph nodes. In stage 4A, the cancer has spread either to the other lung and into fluid around the lungs and heart or as a single tumor to a distant lymph node or organ. In stage 4B, the cancer has spread as multiple tumors to distant lymph nodes or other organs.⁵ Of people who have just received a diagnosis of NSCLC, 40% have stage 4 cancer.¹

Biomarker Testing

Every person's cancer is different. When you are diagnosed with NSCLC, biomarker testing — also called molecular testing — can offer you and your treatment team the information you need to identify the best treatment for your individual case.

Biomarker testing looks for biological changes (also called mutations) in genes or proteins that may be associated with your cancer. In most cases, this involves testing a piece of tissue from the cancer (a biopsy). If you have advanced NSCLC, your doctor may be able to draw your blood from a vein for biomarker testing.⁴

Gene Mutations

Several major organizations recommend that the following genetic biomarkers be tested in all people with NSCLC⁶:

- EGFR⁴
- ALK⁴
- ROS1⁴

Additional genes that are recommended for testing include BRAF, MET, RET, ERBB2 (HER2) and KRAS.⁶ Changes in the BRAF and KRAS genes are more common in people who smoke or who have previously smoked.¹

PD-L1 Expression

The programmed cell death protein 1 ligand (PD-L1) is a protein that can exist on tumor cells and is another biomarker that should be tested in people who receive a diagnosis of NSCLC to determine whether they could respond well to an immunotherapy drug.^{2,7}

If you have not yet received biomarker testing, talk to your doctor about which biomarker tests may be appropriate for you.

Treatment Options

Your treatment team will make recommendations after learning as much as possible about your NSCLC. Understanding the available options can help you have an informed discussion with your doctor.

Options include treatments that are currently standard and others that are available by participating in a clinical trial. Standard treatments include surgery, radiation therapy, chemotherapy, targeted therapy and immunotherapy.²

Surgery

A surgical approach is chosen on the basis of certain considerations, including NSCLC stage and lung function.¹ In some situations, only the tumor and some of the surrounding healthy tissue are removed in a procedure called wedge resection or segmental resection (if a larger portion of tissue is removed). Lobectomies remove an entire section (lobe) of the lung, and pneumonectomies remove an entire lung. A sleeve resection involves removing part of the bronchus.²

Surgery is a standard treatment for stages 0, 1 and 2 NSCLC. However, because of a medical condition, surgery may not be an option for some people. If this is the case for you, and if you have stage 1 or stage 2 NSCLC and adequate lung function, your team may suggest radiation as your primary treatment option. Radiation may also be a preferred option for people who want to avoid surgery.¹

Surgery may also be a part of the standard treatment approach for early stage 3 NSCLC, but only if it is possible to completely remove the tumor and the lymph nodes where the cancer has spread. If you have later-stage 3 (3B and 3C) or stage 4 NSCLC, you will probably not receive surgery as treatment.¹

Radiation Therapy and Chemotherapy

Radiation therapy and chemotherapy treat NSCLC by either killing the cancer cells or preventing them from growing.² NSCLC generally is less responsive to these therapies than is small cell lung cancer.¹

Radiation therapy uses a form of radiation, such as high-energy X-rays, directed at the cancer cells. The therapy can be given through either a machine outside the body or a radioactive substance delivered into the body (eg, through an injection) to the location of the cancer. Chemotherapy involves administering a drug either systemically (taken orally or injected into a vein or muscle) or

regionally (injected directly into a local area such as a body cavity or organ).²

For stages 1 and 2 NSCLC, radiation therapy can replace surgery. If you receive surgery, chemotherapy may be given before and/or after surgery.¹

For stage 3 NSCLC, radiation therapy and chemotherapy can be given alone or in combination.¹

For NSCLC that either is stage 4 or has returned, you would likely receive radiation only for symptom management. Chemotherapy may be used alone or in combination with either other chemotherapies or other types of drugs.¹

Targeted Therapy

Targeted drugs typically are used to treat NSCLC that is stage 4 or has returned.^{1,2} They are designed to recognize and attack the specific cancer cells with changes in their proteins or genes (such as EGFR, ALK and ROS1) that have been identified through biomarker testing (see *Biomarker Testing* section above). With their ability to focus on cancer cells, targeted drugs usually cause less damage to normal cells than does chemotherapy or radiation.⁴

Two types of targeted drugs used to treat NSCLC are tyrosine kinase inhibitors and monoclonal antibodies. These drugs work in different ways to attack your cancer cells. Tyrosine kinase inhibitors enter the cancer cell through the cell membrane and then stop signals that cause the cell to grow and divide. Monoclonal antibodies attach to a specific part of the cancer cell and then either kill the cell or stop it from growing or spreading.²

Immunotherapy

Immunotherapy describes biologic drugs that stimulate your immune system to fight cancer cells. Some monoclonal antibodies are a type of immunotherapy called immune checkpoint inhibitors. Some immune checkpoint inhibitors target PD-L1 on cancer cells, which may respond particularly well if the tumor expresses a high amount (50% or more) of PD-L1. Your doctor can determine the level of PD-L1 expression on your tumor with a biomarker test (see *Biomarker Testing* section above).^{2,7}

Other immune checkpoint inhibitors target the programmed cell death protein 1 (PD-1), which is found on T cells in the immune system. When PD-1 attaches to PD-L1, the T cell is unable to kill the cancer cell. Immune checkpoint inhibitors can prevent this attachment.^{2,7}



Another protein on T cells called the CTLA-4 can also be targeted by certain immune checkpoint inhibitors.⁸

Clinical Trials

At various locations in the United States, clinical trials are being conducted to test the safety and effectiveness of new treatments and to see whether they are better than standard ones. Those being studied include new treatments and combinations of treatments, radiosensitizers (substances that increase the effectiveness of radiation therapy) and chemoprevention substances (such as drugs or vitamins) that could help prevent NSCLC from returning.²

Talk to your doctor about whether participating in a clinical trial might be the best approach. You can review current clinical trials for NSCLC treatment that are supported by the National Cancer Institute here: <https://www.cancer.gov/about-cancer/treatment/clinical-trials/disease/non-small-cell-lung/treatment>.



Health, Diet and Emotional Support

THERE ARE STEPS YOU can take during your journey to help address emotional needs and cope with treatment side effects. After receiving a diagnosis of NSCLC, you may consider changes to diet and lifestyle. The following information provides suggestions to help you stick to your treatment plan and manage side effects associated with treatment. It is important to consult with your doctor before beginning anything new.

Health

Throughout treatment, it is not uncommon for people to experience side effects, such as fatigue, that can make it difficult to accomplish daily tasks. To help reduce fatigue and to improve your health, physically and mentally, health care professionals suggest exercise.

If beginning or continuing an exercise program after a recent diagnosis of NSCLC, discuss your plans and the intensity of the intended workout with your health care professional, who can help you determine a safe, effective plan. Certain factors, such as the extent of your cancer, your treatment regimen and overall stamina, can affect your ability to exercise. Therefore, when exercising, be sure to listen to your body. It is OK to take a day off and rest when necessary. If you experience any side effects while exercising, be sure to discuss them with your health care professional immediately.

Diet

Proper nutrition is beneficial during treatment and after it ends. A balanced diet can help you maintain a healthy body weight, energy and strength; better tolerate the side effects of treatment; and fight infection. Your diet should include a variety of nutritious foods, such as healthy proteins,

carbohydrates, fats, vitamins and minerals. Be sure to drink plenty of water.

During and after treatment, you may experience side effects that make it difficult to practice healthy eating habits. Common side effects of treatment include loss of appetite, sore mouth or throat, dry mouth, dental and gum problems, changes in taste or smell, nausea, vomiting, diarrhea, constipation, fatigue and depression. To help avoid these side effects, ask your health care professional how to prepare nutritionally before treatment begins. Should you experience any side effects, discuss them with your treatment team immediately.

Emotional Support

For a person with cancer, openly communicating with your loved ones, caregiver(s) and health care professionals is important. It is equally important not to hide your feelings or deny the need to talk to someone. Some people find that by talking, they begin to solve problems and think about other issues as their family and friends ask questions. Friends, family and caregivers can share their strength and concern with you and help encourage you as well.

Joining a local support group and connecting with other patients with cancer can allow you to share your concerns and hear from others on a similar journey. Additionally, patients who speak regularly with their health care professionals are more proactive and likely to be satisfied with their overall care. These patients tend to be more informed and more likely to complete therapy, and find it easier to adjust to changes in care.

As you move forward with your NSCLC journey, take advantage of the resources starting on page 17 for additional information and support.

Questions to Ask Your Health Care Team

What kind of NSCLC do I have?

Where exactly is the cancer? Has it spread beyond where it started, and if so, where?

What is the stage of my cancer, and what does that mean in my case?

Will I need any other tests before we can decide on treatment?

Should my blood or tumor tissue be sent for biomarker/molecular testing?

Has the cancer been checked for gene changes that could help you choose my treatment options?

Do I need to see any other doctors or health professionals?

If I am concerned about the costs and insurance coverage for my diagnosis and treatment, who can help me?

What are my treatment choices?

What treatments do you recommend and why?

What is the goal of treatment?

Should I get a second opinion? How do I do that? Can you recommend someone?

Are there any clinical trials that are appropriate for me? If so, how do I get more information?

What are the chances my cancer can be cured with these treatment options?

How quickly do I need to decide on treatment?

What should I do to be ready for treatment?

How long will my treatment last? What will treatment be like? Where will my treatment be done?

Will treatment affect my daily activities?

What would my options be if the treatment does not work or if the cancer comes back (recurs) after treatment?

How will we know whether the treatment is working?

What are the risks and side effects with the treatments you suggest?

How long are the side effects likely to last, and how can I manage them?

Is there anything I can do to help manage side effects?

What symptoms or side effects should I tell you about immediately?

Whom can I reach out to if I experience a problem or have an urgent question outside usual office hours – for example, during nights, holidays or weekends?

Do I need to change what I eat during treatment?

Are there any limits on what I can do?

Can you suggest a mental health professional I can see if I start to feel overwhelmed, depressed or distressed?

What symptoms should I watch for?

What kind of exercise should I do now?

What type of follow-up will I need after treatment?

How often will I need to have follow-up examinations and imaging tests?

Will I need any blood tests?

How will we know whether the cancer has come back? What should I watch for?

What will my options be if the cancer comes back?

Are there support groups available for me and my loved ones?

Where can I get financial help?

Where can I get treatment-related help such as wigs or transportation to appointments?

Do you have a social worker or patient navigator who can help me? Or can you refer me to one?

Where can I get more information about lung cancer?

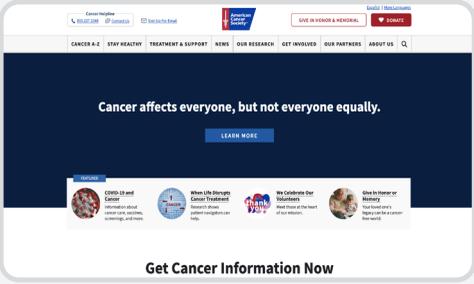
American Cancer Society

www.cancer.org

The American Cancer Society is a global grassroots force of 1.5 million volunteers dedicated to saving lives, celebrating lives and leading the fight for a world without cancer. From breakthrough research to free lodging near treatment, a 24/7/365 live helpline, free rides to treatment and convening powerful activists to create awareness and impact, the society is the only organization attacking cancer from every angle.

Resource Checklist

- ✓ Cancer basics and general information
- ✓ Latest research updates
- ✓ Downloadable PDFs



ADDRESS
250 Williams St. NW
Atlanta, GA 30303

CONTACT INFO
Phone: 800-227-2345
Online chat available

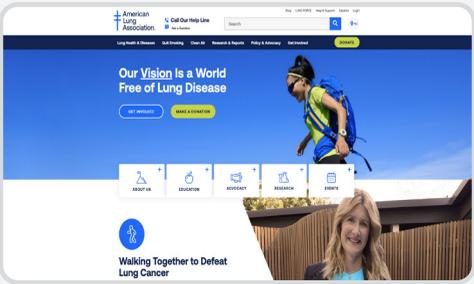
American Lung Association

www.lung.org

The American Lung Association aims to save lives by supporting lung health and preventing lung disease. It offers education, advocacy and research related to lung health. The association is dedicated to defeating lung cancer, supporting clean air for everyone, addressing concerns with tobacco and improving quality of life for people with lung disease and their families.

Resource Checklist

- ✓ Lung Action Network
- ✓ Lung disease initiatives
- ✓ Lung Help Line



ADDRESS
55 W. Wacker Drive
Suite 1150
Chicago, IL 60601

CONTACT INFO
Phone: 800-586-4872
Email: Online form



ADDRESS

1801 Research Blvd.
Suite 400
Rockville, MD 20850

CONTACT INFO

Phone: 301-984-9496
Email: Online form

Association of Community Cancer Centers

www.accc-cancer.org

The Association of Community Cancer Centers (ACCC) has over 25,000 multidisciplinary practitioners and 2,100 cancer programs and practices nationwide that support an estimated 65% of the nation's cancer patients. ACCC connects all members of the cancer care community through their education and advocacy organization.

Resource Checklist

- ✓ Blog posts and podcasts
- ✓ Updated news releases
- ✓ Educational resources



ADDRESS

275 Seventh Ave.
New York, NY 10001

CONTACT INFO

Phone: 800-813-HOPE (4673)
Email: info@cancercare.org

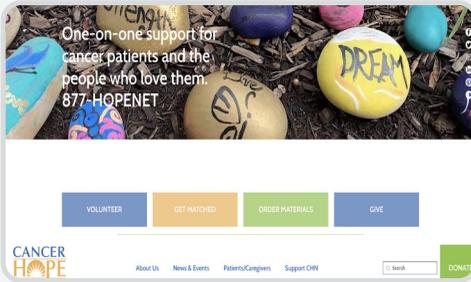
CancerCare

www.cancercare.org

CancerCare has been providing free, professional support services and credible information for patients with cancer since 1944. This organization offers resources including financial, emotional and practical support. CancerCare offers case management, support groups and counseling provided by oncology social workers and experienced cancer experts.

Resource Checklist

- ✓ Counseling and support groups
- ✓ Information by cancer type
- ✓ Financial assistance resources



ADDRESS

2 North Road
Suite A
Chester, NJ 07930

CONTACT INFO

Phone: 877-HOPENET

Email: info@cancerhopenetwork.org

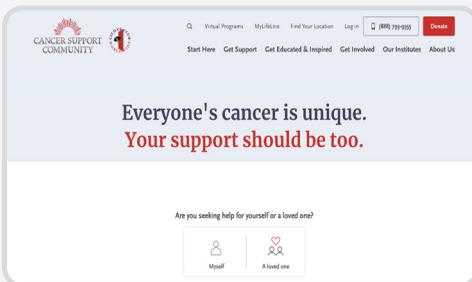
Cancer Hope Network

www.cancerhopenetwork.org

Cancer Hope Network (CHN) is a nonprofit dedicated to making sure no one faces cancer alone through free one-on-one confidential support to all people, whether they be patients, family or friends. CHN has been training cancer survivors and caregivers as support volunteers for 40 years. Your matched volunteer will be with you through diagnosis, treatment and recovery.

Resource Checklist

- ✓ One-on-one support
- ✓ Trained volunteers
- ✓ Regular events and fundraisers



ADDRESS

5614 Connecticut Ave. NW
Suite 280
Washington, DC 20015

CONTACT INFO

Phone: 202-659-9709

Cancer Helpline: 888-793-9355

Email: Online form

Cancer Support Community

www.cancersupportcommunity.org

The Cancer Support Community is dedicated to helping all people affected by cancer with award-winning education, a toll-free helpline and multiple emotional, psychological and financial support services. In 2018, it welcomed a Denver-based nonprofit, MyLifeLine, which is an online community with over 30,000 patients, caregivers and supporters.

Resource Checklist

- ✓ Cancer support resources (online and in person)
- ✓ Blog and radio show
- ✓ MyLifeLine online community

Caregiver Action Network

caregiveraction.org

The Caregiver Action Network is a nonprofit that offers education, support and resources to the more than 90 million Americans who care for loved ones who have disease or disability.

Caregivers supported by the network include parents, families and friends of wounded soldiers and adult children caring for parents with Alzheimer's disease.

Resource Checklist

- ✓ Caregiver help desk
- ✓ Community and forums
- ✓ Support from other caregivers



ADDRESS

1150 Connecticut Ave. NW
Suite 501
Washington, DC 20036-3904

CONTACT INFO

Phone: 202-454-3970

Caregiver Help Desk: 855-227-3640

Email: info@caregiveraction.org

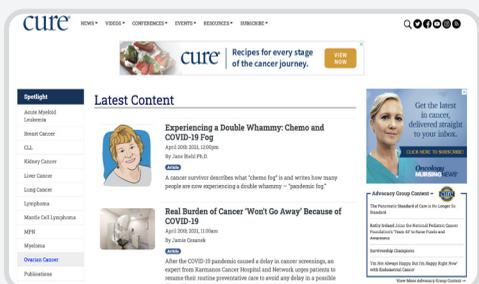
CURE Media Group

www.CUREtoday.com

CURE Media Group's magazine, *CURE*[®], and CUREtoday.com offer leading resources and information that serve as a guide to every stage of the cancer experience. *CURE*[®] combines science, humanity and technology to help make cancer understandable for patients and their caregivers, to connect the cancer community and to empower individual journeys.

Resource Checklist

- ✓ Cancer news, research and education
- ✓ Healers and Heroes events
- ✓ Advocacy groups



ADDRESS

2 Clarke Drive
Suite 100
Cranbury, NJ 08512

CONTACT INFO

Phone: 609-716-7777

GO2 Foundation for Lung Cancer

go2foundation.org

Founded by patients and survivors, GO2 Foundation for Lung Cancer transforms survivorship as the world's leading organization dedicated to saving, extending and improving the lives of those vulnerable, at risk and diagnosed with lung cancer. This organization's trained and compassionate team provides tailored support to help guide patients and their loved ones every step of the way.

Resource Checklist

- ✓ 1800 Lung Cancer Helpline
- ✓ Phone Buddy peer-to-peer mentoring
- ✓ LungMATCH treatment and clinical trial navigation



ADDRESS

1050 Connecticut Ave. NW
PO Box 65860
Washington, DC 20035

1100 Industrial Rd., #1
San Carlos, CA 94070

CONTACT INFO

Phone: 202-463-2080

Cancer Helpline: 800-298-2436

Email: info@go2foundation.org

Help for Cancer Caregivers

www.helpforcancercaregivers.org

Help for Cancer Caregivers is a collaborative effort among organizations to provide caregivers of individuals with cancer the support they need to improve their well-being and health. Through a wealth of resources, such as articles, books and an easily navigable website, geared toward specific struggles a caregiver might face, Help for Cancer Caregivers is dedicated to making sure caregivers are cared for as well.

Resource Checklist

- ✓ Private and personal care guide
- ✓ Resource library
- ✓ Advocacy connector



ADDRESS

N/A

CONTACT INFO

Email: Online form



ADDRESS

PO Box 754
Chicago, IL 60690

CONTACT INFO

Phone: 312-407-6100

Lung Cancer Helpline: 844-360-5864

Email: info@LUNgevity.org

LUNgevity

www.lungevity.org

LUNgevity is dedicated to improving outcomes for individuals with lung cancer. It funds scientific research and offers educational resources, online peer-to-peer support and survivorship programs that are held in person. It holds more than 80 grassroots awareness and fundraising events each year.

Resource Checklist

- ✓ Private and personal care guide
- ✓ Resource library
- ✓ Advocacy connector



CONTACT INFO

Phone: 800-422-6237

Email: NCIinfo@nih.gov

Live chat available

National Cancer Institute

www.cancer.gov

The U.S. National Cancer Institute's website provides accurate, up-to-date information about many types of cancer, information about clinical trials, resources for people dealing with cancer and information for researchers and health professionals.

Resource Checklist

- ✓ Private and personal care guide
- ✓ Resource library
- ✓ Advocacy connector

Website	Address	Contact Information
American Cancer Society www.cancer.org	250 Williams St. NW Atlanta, GA 30303	Phone: 800-227-2345 Online chat available
American Lung Association www.lung.org	55 W. Wacker Drive, Suite 1150 Chicago, IL 60601	Phone: 800-586-4872 Email: Online form
Association of Community Cancer Centers www.accc-cancer.org	1801 Research Blvd., Suite 400 Rockville, MD 20850	Phone: 301-984-9496 Email: Online form
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Help for Cancer Caregivers www.helpforcancercares.org	N/A	Email: Online form
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