Advanced Lung Cancer

Why there’s more hope than ever!

- Immunotherapy: A look at this breakthrough treatment
- Inspiring real-life stories
- Tools to help you get the best care

Getting the support you need p. 18
Tips for the patient—and the caregiver

“Cancer, you’re not beating me!”

Four years after her stage IV diagnosis, Ivy Elkins is making the most of each day
**Advanced Lung Cancer**

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Special thanks to

Deepa Rangachari, MD, medical oncologist specializing in lung cancer, Beth Israel Deaconess Medical Center in Boston, MA; Instructor of Medicine at Harvard Medical School

American Lung Association
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“Standing up to lung cancer”

“Get screened!”
   “When you are [getting] a checkup, get a chest X-ray because lung cancer ain’t going to tell you it’s there, but a simple chest X-ray will.”
   —newsman Larry King, urging others to be proactive after his recent lung cancer diagnosis

“Stay in the moment”
   “This diagnosis makes you live one day at a time, and that’s what everyone should do: Live moment to moment to moment.”
   —actress Valerie Harper, whose lung cancer spread to her brain, on staying focused on what really matters

“Give thanks!”
   “Did I think I’d ever make it to see this? Hell no! Someone up there must like me. And luckily someone down here likes me, too.”
   —Rolling Stone Ronnie Wood on his successful treatment for lung cancer

20 Donna and Robert tell their family:
   Don’t worry.
**Loving life—despite advanced non-small cell lung cancer**

Today’s treatments mean there’s still plenty of time to experience everyday joys and make lasting memories.

These days, Gloria is busy putting the finishing touches on the 45th wedding anniversary party she’s been planning for herself and her husband, Bill. Joining in the celebration will be the family that means everything to her—particularly her two daughters: Carly, married with children, and Jill, newly engaged—and the friends that make sense for you.

T

although Gloria is now thriving, her story can inspire others. She’s a living example of what can happen when a patient’s determination, a compassionate medical team, and modern medicine come together.

Taking a step back, how did we get to this point? A look at the lungs

**BREAKTHROUGH!**

Immunotherapy is extending lives!

PD-1 inhibitors—the newest immunotherapy drugs to be approved by the FDA—are bringing new hope to certain non-small cell lung cancer patients in whom traditional chemo has failed. Given intravenously, these medications work by allowing the immune system to detect and attack cancer cells.

In stage III NSCLC, cancer spreads beyond the lung to the chest wall, diaphragm or more distant chest lymph nodes. In stage IV NSCLC, cancer spreads to more distant parts of the body, such as the brain, liver or adrenal glands. Not too long ago, advanced NSCLC was considered untreatable; but today, as Gloria’s story shows, that is no longer the case for many patients.

### Understanding NSCLC

Lung cancer begins when abnormal cells in the organ begin to multiply, causing tumors to form. Sometimes, cancer cells invade the bloodstream and lymphatic system, allowing the disease to spread (metastasize) elsewhere in the body. NSCLC accounts for the overwhelming majority (45%) of lung cancer cases, and there are three main types:

1. *Adenocarcinoma*—usually found in the outer part of the lung; the majority (85%) of lung cancer cases.
2. *Squamous cell carcinoma*—found in flat cells that line the lung’s airways.
3. *Large cell carcinoma*—a fast-growing type that can appear anywhere in the lung.

### Spreading the signs

Unfortunately, NSCLC does not usually cause noticeable symptoms until it’s progressed considerably. By that time, you may experience a chronic cough, blood in the phlegm, fever, fatigue, weight loss, chest pain and shortness of breath.

In order to determine if you have lung cancer, your healthcare provider may order the following tests:

1. **Imaging scans:** X-rays and CT scans are the most commonly recommended to make a lung cancer diagnosis.

### Biopsy

A small amount of tissue is removed from your lungs or—in some cases—a nearby lymph node to test for cancer cells. NSCLC is considered advanced when it has metastasized to other parts of the body; causing symptoms such as bone pain, headache, seizures, weakness or numbness in the arms or legs, jaundice and lumps below the skin.

As if dealing with the emotional roller coaster experience away from me,” says Gloria. “All these things I would have missed—Carly’s wedding, the birth of my two beautiful granddaughters, Bill’s upcoming wedding and, now, the party for Bill and me—well, I can’t even express how it feels. I no longer wake up thinking I have cancer. Instead, I wake up wondering what’s on my calendar today? It’s the most wonderful feeling in the world!”

**Where do you fit in?**

Whether you’ve been newly diagnosed with advanced non-small lung cancer (NSCLC), your disease has progressed during treatment or recurred following treatment, take comfort and inspiration from Gloria’s story. Fact is, the last few years have seen a surge of effective new treatments for NSCLC, which have allowed thousands of people like Gloria to live longer than most oncologists might have imagined just a decade ago. Ready to take aim at your cancer? Continue reading this guide, then discuss all your options with your oncologist in order to come up with a treatment strategy that makes sense for you.

*Adenocarcinoma* is considered advanced when it has metastasized to other parts of the body; causing symptoms such as bone pain, headache, seizures, weakness or numbness in the arms or legs, jaundice and lumps below the skin.

**A look at the lungs**

Ask your doctor to show you where your lung cancer is.

**RIGHT LUNG**

*Superior lobe*  
*Primary bronchus*

**SECONDARY BRONCHUS**

**BRONCHIOLES**

**SECONDARY BRONCHUS**

**LEFT LUNG**

*Primary bronchus*  
*Middle lobe*

**Inferior lobe**  
*Alveoli*
Treating advanced NSCLC

When determining your treatment plan, your oncologist will consider several factors, including your cancer’s stage, your age, your lung function and overall health, and the likelihood that a particular treatment will work and your feelings about it—e.g., how willing you are to deal with the side effects and any down time associated with it. Your doctor will also consider any treatments you’ve already had and what, if any, genetic mutation you may have.

Currently, the treatment options for advanced stage III and stage IV lung cancers include:

- **Chemotherapy**, taken orally or by injection. It enters the bloodstream and fights cancer cells bodywide.
- **Radiation**, in which high-energy X-rays are used to shrink tumors and target and destroy cancer cells that may have spread elsewhere in the body.
- **Surgery**: Although surgery is rarely used to treat advanced stage lung cancers, it may be used to remove lung cancer cells that have spread elsewhere in the body.
- **Targeted therapy**, which uses medication to zero in on specific gene mutations in lung cancer cells. Unlike chemotherapy, these drugs do not affect the entire body.
- **Immunotherapy**, which helps the immune system detect and destroy cancer cells. The latest immunotherapies are a key option for certain patients in whom chemo has failed. (See next page for more.)

**Is a clinical trial right for you?**

When NSCLC spreads to the lymph nodes that are near the other lung or in the neck, grows within the chest, or spreads to other organs or sites in the body, a clinical trial may be an excellent option. Clinical trials generally involve newer treatments, such as targeted therapy and immunotherapy, or new combinations of treatments. If NSCLC progresses during treatment or recurs following treatment, a different chemo drug or targeted therapy (or a combination of the two) or an immunotherapy may better treat your cancer. Palliative therapies, aimed at relieving uncomfortable symptoms, may also be used. In any case, your healthcare team has a greater arsenal of cancer-fighting treatments than ever before that can help you, like Gloria, get back to the business of loving life! 🌟

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**Immunotherapies—at a glance**

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<th>Therapy</th>
<th>How it works</th>
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<td>Monoclonal antibodies</td>
<td>These man-made versions of immune system proteins can be used to target a specific part of a cancer cell.</td>
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<tr>
<td>Checkpoint inhibitors</td>
<td>Cancer cells can sometimes manipulate molecules (aka “checkpoints”) on immune cells so the immune cells won’t recognize and attack them. Checkpoint inhibitors target these molecules, enabling the immune system to recognize and attack the cancer.</td>
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<td>Cancer vaccines</td>
<td>Treatment (vs. preventive) vaccines boost your immune system’s response to cancer cells.</td>
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<td>Cytokines help your immune system fight cancer cells; they may be used alone or in combination with other treatment, such as chemotherapy.</td>
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<tr>
<td>Other immunotherapies</td>
<td>Additional therapies to fight a variety of cancers are available; some are being studied in clinical trials.</td>
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“I’m enjoying life—despite stage IV lung cancer”

Thanks to cutting-edge treatments, Ivy is able to manage her cancer like a chronic condition—and make the most of every day! —BY AMY CAPETTA

Active and upbeat, 51-year-old Ivy Elkins loves taking vacations with her husband and two teenage boys, laughing with girlfriends over a glass of wine, doing advocacy work and trying adventurous activities, like horseback riding. And not even the stage IV non-small cell lung cancer she’s been living with for the last four years can stand in her way!

It all started in mid-2013 when the Chicago-area resident began dealing with neck pain and elbow stiffness, bothersome symptoms she chalked up to stress from planning her son’s bar mitzvah. But when she couldn’t take the discomfort anymore, she headed to her primary care physician.

During the next few months, she was referred to two physical therapists, two orthopedists and a rheumatologist. And when the results from an MRI came in, they revealed a mass on her elbow. A subsequent biopsy came back positive for adenocarcinoma, a malignant tumor that forms in the mucus-secreting glands that line the inside of organs. And on December 26, Ivy learned she had stage IV lung cancer. “I was completely blindsided.”

Lean and learn
Luckily, Ivy’s friends introduced her to a woman in the area who had been diagnosed with the same disease six years earlier. “She talked to me about the advances in research and made me realize there was hope,” she says.

Most important of all, she put Ivy in touch with an oncologist she clicked with right away. When another MRI indicated that Ivy also had eight tiny spots on her brain, her doctor suggested she start a new therapy immediately. Sure enough, the results from her first follow-up scans were incredible: The tumor on her lung shrank! “And this was possible without surgery,” she says.

Take back control
Almost three years later, Ivy was put on yet another treatment, which has given her even better results and further reduced the mass on her lung. Feeling "absolutely fine," she’s been involved with LUNGevity Foundation—raising money for lung cancer research, attending and speaking at conferences, and mentoring—and bonding with—other women. “I call them my lung cancer girlfriends, and these relationships have been huge for me,” she says.

Today, Ivy looks to the future with optimism. Her number one message for others: Be in tune with your body. “If you feel that something isn’t right—no matter what others might say—investigate what is going on. It could have been so different for me if I hadn’t listened to myself.”

TURN FOR IVY’S TIPS
**You can live each day to the fullest, too!**

Here, Ivy shares her top tips—ask your care team if they can help.

**Become an informed patient.**
Since the Internet can be a gloomy place, many patients are told to avoid Googling “lung cancer.” Ivy suggests asking your doctor to recommend reputable websites and books in order to learn about this disease. “There are lots of new words thrown around as soon as you are diagnosed, and the more familiar you become with this vocabulary, the more you can be your own advocate and ask better questions.”

**Include your family and friends on your journey.**
Although your loved ones may not fully understand what you’re going through, Ivy feels it’s important to keep the lines of communication open. “Make sure you share your feelings with them so that resentment doesn’t develop on either side,” she says. “I don’t look like a stereotypical cancer patient, so most people don’t know what I’m going through unless I talk to them about it.”

**Find the right oncologist for you.**
“It’s imperative to feel that your oncologist is on top of advances in the lung cancer field, open to all of your questions and spends enough time with you,” she says. “Ideally, you want a doctor you can trust because you’re going to have a long-term relationship with him or her. I can’t tell you how lucky I feel. Good treatment prescribed by an amazing oncologist who’s made all the right decisions has gotten me to where I am today.”

**Say “yes” to enjoying life.**
“Don’t hesitate to plan things or make decisions because of your lung cancer,” says Ivy. “Many of us are on medication that allows us to feel fairly normal while on treatment. So eat the good food, drink the good wine (with your doctor’s permission), accept the job and take the vacation! I remind myself every day that no one knows how long they will be on this earth, which is why it’s important to make the most of each day.”

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**Q&A: Answers to your most pressing questions about advanced non-small cell lung cancer**

**Can I pass this on to my kids?**
*Q* After I was diagnosed with advanced non-small cell lung cancer, I tested positive for an EGFR gene mutation. Should my children get tested, too?
*A* Most likely, no. EGFR mutations are seen in about 15% of advanced non-small-cell lung cancer, and in the vast majority of cases, the genetic abnormality is restricted to the cancer cells—in other words, it is not “passed down” from one family member to another. The bottom line: Your EGFR mutation does not put your children at increased risk, so formal genetic counseling is not necessary. That said, testing might be warranted if you were diagnosed at a young age, or if you have several family members who have been affected by lung or other cancers, especially if they never smoked.

**Is a multivitamin ok?**
*Q* Will I need to stop taking my multivitamin once I start treatment for my advanced lung cancer?
*A* No. Adhering to a healthy lifestyle—which includes taking your multivitamin—is an important part of your cancer treatment plan. However, do talk with your physicians about all the over-the-counter and herbal supplements you are currently taking. This can help you avoid drug interactions that may increase the risk of side effects or reduce the effectiveness of your treatment.

**Supporting a loved one**
I’m writing about my husband, who’s in treatment for stage IV lung cancer. He’s very moody, often irritable, and seems unable to enjoy anything. But he insists that he’s fine. How can I help him?
*Q* You and your husband are going through a lot, and his response to this extremely difficult situation is common among people with advanced cancer. I strongly encourage you and your husband to share your feelings and experiences with your cancer care team. It may actually help for you to call and discuss your concerns ahead of time. The medical team can then broach the topic of your husband’s emotions at his next exam and help him to open up.

**OUR EXPERT:**
Deepa Rangachari, MD, is a medical oncologist specializing in lung cancer at Beth Israel Deaconess Medical Center in Boston, MA, and Instructor of Medicine at Harvard Medical School.
What does OPDIVO® treat? OPDIVO (nivolumab) is a prescription medicine used to treat people with a type of advanced stage lung cancer (called non-small cell lung cancer) that has spread or grown and you have tried chemotherapy that contains platinum, and it did not work or is no longer working. If your tumor has an abnormal EGFR or ALK gene, you should have also tried an FDA-approved therapy for tumors with these abnormal genes, and it did not work or is no longer working. It is not known if OPDIVO is safe and effective in children less than 18 years of age. It is not known if OPDIVO is safe and effective in women who are breastfeeding.

Important Safety Information for OPDIVO® (nivolumab) OPDIVO is a medicine that may treat certain cancers by working with your immune system. OPDIVO can cause your immune system to attack normal organs and tissues in any area of your body and can affect the way they work. These problems can sometimes become serious or life-threatening and can lead to death. These problems may happen anytime during treatment or even after your treatment has ended. Serious side effects may include:

- Lung problems (pneumonitis). Symptoms of pneumonitis may include: New or worsening cough; chest pain; and shortness of breath.
- Intestinal problems (colitis) that can lead to tears or holes in your intestines. Symptoms of colitis may include: Diarrhea (loose stools) or more bowel movements than usual; blood in your stools or dark, tarry, sticky stools; and severe stomach area (abdomen) pain or tenderness.
- Liver problems (hepatitis). Signs and symptoms of hepatitis may include: Yellowing of your skin or the whites of your eyes; severe nausea or vomiting; pain on the right side of your stomach area (abdomen); droniness; dark urine (tea colored); bleeding or bruising more easily than normal; and feeling less hungry than usual.
- Kidney problems, including nephritis and kidney failure. Signs of kidney problems may include: Decrease in the amount of urine; blood in your urine; swelling in your ankles; and loss of appetite.
- Skin problems. Signs of these problems may include: Rash; itching; skin blistering; and lesions in the mouth or other mucous membranes.
- Inflammation of the brain (encephalitis). Signs and symptoms of encephalitis may include: Headache; fever; tiredness or weakness; confusion; memory problems; sleepiness; or hearing or seeing things that are not really there (hallucinations), seizures, and stiff neck.
- Problems in other organs. Signs of these problems may include: Changes in eyesight; severe or persistent muscle or joint pains; and severe muscle weakness.
- Getting medical treatment right away may keep these problems from becoming more serious.
- Liver problems (hepatitis). Signs and symptoms of hepatitis may include: Yellowing of your skin or the whites of your eyes; severe nausea or vomiting; pain on the right side of your stomach area (abdomen); droniness; dark urine (tea colored); bleeding or bruising more easily than normal; and feeling less hungry than usual.
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For Previously Treated Advanced Non-Small Cell Lung Cancer (NSCLC) Patients This is Big. A Chance to Live Longer.

- OPDIVO® demonstrated longer life in clinical trials for adults with advanced NSCLC previously treated with platinum-based chemotherapy.
- OPDIVO has been prescribed to more than 40,000 of these patients.
- OPDIVO significantly increased the chance of living longer vs chemotherapy (docetaxel).
- OPDIVO works with your immune system.

OPDIVO was studied in adults with advanced NSCLC previously treated with platinum-based chemotherapy. In Trial 1 (Squamous) with 222 people, half the patients on OPDIVO (n=135) were still alive at 9.2 months, compared to 6 months with chemotherapy (docetaxel) (n=137).

In Trial 2 (Non-squamous) with 582 people, half the patients on OPDIVO (n=292) were still alive at 12.2 months, compared to 9.4 months with chemotherapy (docetaxel) (n=290).

A Chance To Live Longer. Talk to your doctor today about OPDIVO.

OPDIVO will not work for every patient. Individual results may vary.

Learn more about this and other indications at OPDIVO.com or 1-855-OPDIVO-1.

Your healthcare provider will check you for these problems during treatment. Your healthcare provider may treat you with corticosteroid or hormone replacement medicines. Your healthcare provider may also need to delay or completely stop treatment, if you have severe side effects.

OPDIVO can cause serious side effects, including:

- Severe infusion reactions. Tell your doctor or nurse right away if you get these symptoms during an infusion of OPDIVO: Chills or shivering; itching or rash; flushing; difficulty breathing; dizziness; fever; and feeling like passing out.

Pregnancy and Nursing: Tell your healthcare provider if you are pregnant or plan to become pregnant. OPDIVO can harm your unborn baby. Females who are able to become pregnant should use an effective method of birth control during and for at least 5 months after the last dose of OPDIVO. Talk to your healthcare provider about birth control methods that you can use during this time. Tell your healthcare provider right away if you become pregnant during treatment. Before receiving treatment, tell your healthcare provider if you are breastfeeding or plan to breastfeed. It is not known if OPDIVO passes into your breast milk. Do not breastfeed during treatment.

- All the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements.
- The most common side effects of OPDIVO when used alone include: Feeling tired; pain in muscles, bones, and joints; diarrhea; weakness; shortness of breath; decreased appetite; upper respiratory tract infection; rash; itchy skin; nausea; cough; constipation; back pain; and fever.

These are not all the possible side effects. For more information, ask your healthcare provider or pharmacist. Call your doctor for medical advice about side effects. You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088. You may also report side effects to Bristol-Myers Squibb at 1-800-721-5072.

Please see Important Facts for OPDIVO on the following page.
The information below does not take the place of talking with your healthcare professional. Only your healthcare professional knows the specifics of your condition and how OPDIVO® may fit into your overall therapy.

Talk to your healthcare professional if you have any questions about OPDIVO® (nivolumab).

**What is the most important information I should know about OPDIVO® (nivolumab)?**

OPDIVO® is a medicine that may treat certain cancers by working with your immune system. OPDIVO® can cause your immune system to attack normal organs and tissues in any area of your body and can affect the way they work. These problems can sometimes become serious or life-threatening and can lead to death. These problems may happen anytime during treatment or even after your treatment has ended. Call or see your healthcare provider right away if you develop any symptoms of the following problems or these symptoms get worse:

- **Lung problems (pneumonitis).** Signs of pneumonitis may include:
  - new or worsening cough
  - chest pain
  - shortness of breath
- **Intestinal problems (colitis).** Signs of these problems may include:
  - changes in bowel habits or blood in your stools
  - abdominal pain or cramps
- **Kidney problems, including nephritis and kidney failure.** Signs and symptoms of kidney problems may include:
  - difficulty urinating
  - blood in your urine
  - swelling in your legs or ankles
  - rash

**What is OPDIVO®?**

OPDIVO® is a prescription medicine used to treat people with a type of advanced stage lung cancer (non-small cell lung cancer) that did not respond to other treatments. OPDIVO® is also used to treat people with tumors that have spread or grown, and you have also tried an FDA-approved chemotherapy drug that did not work or is no longer working.

**What are the possible side effects of OPDIVO®?**

OPDIVO® can cause serious side effects, including:

- **Severe infection reactions.** Tell your doctor or nurse right away if you get these symptoms during an infusion of OPDIVO®:
  - chills or shivering
  - itching or rash
  - fever
  - feeling like passing urine
  - difficulty breathing out

The most common side effects of OPDIVO® when used alone may include:

- feeling tired
- pain in muscles, bones, and joints
- diarrhea
- weakness
- shortness of breath
- decreased appetite
- upper respiratory tract infection

These are not all the possible side effects of OPDIVO®. For more information, talk with your healthcare provider or pharmacist. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

**How will I receive OPDIVO®?**

Your healthcare provider will give you OPDIVO® in your vein through an intravenous (IV) line over 60 minutes.

**What should I tell my healthcare provider before receiving OPDIVO®?**

Before you receive OPDIVO®, tell your healthcare provider if you:

- have immune system problems such as Crohn’s disease, ulcerative colitis, or lupus
- have an organ transplant
- have lung or breathing problems
- have liver problems
- have other medical conditions
- are pregnant or plan to become pregnant. OPDIVO® can harm your unborn baby.
- are breastfeeding or plan to breastfeed. It is not known if OPDIVO® passes into your breast milk. Do not breastfeed during treatment with OPDIVO®.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Know the medicines you take. Keep a list of them to show your healthcare providers and pharmacist when you get a new medicine.

**How will I be the CEO of my health?**

Just like a company, choose the right employees—and yes, your medical team technically works for you,” says Jill. “Discuss your overall health with your doctors, give them autonomy and trust their expertise, but keep checks and balances. You are a patient—not a disease, and we all have different experiences and needs. Statistics are for research, so as a patient, the only statistics that count are 0% or 100%.”

**Find your happy place.**

“I work at a camp every summer in Culver, IN, which is where I went to camp as a kid,” says Jill. “When I was 13, my dad died of lung cancer in the spring, so I couldn't wait to get back to Culver where I could escape reality and pretend my life was normal for a few months. I call it ‘Gumdrop and Lollipop Land!’ Today, 34 years later, it hasn’t changed. When I’m at camp, I get a ‘breather’ from lung cancer—I’m able to take a break and recharge, both physically and emotionally. I know everyone can’t go to camp, but they can find an hour each day or several times a week to escape.”

**Take a 360 approach!**

Jill Feldman, Deerfield, IL.

Diagnosed with stage I lung cancer in 2009; diagnosed with stage IV lung cancer in 2012.

“Tell me what you have, and I will treat you accordingly.”

Jill Feldman, Deerfield, IL.

Diagnosed with stage I lung cancer in 2009; diagnosed with stage IV lung cancer in 2012.

**Regain a sense of control.**

Managing stage IV lung cancer since 2012. Jill is adamant about how she copes: “I refuse to let it control my emotions, steal my joy, take away precious time with my kids, or dictate how I live.” She says, “I found that my greatest weapon against fear was changing my mindset—because that is something I can control. While I can’t control the future, I try to consciously embrace and believe in my what-I-know today mindset. It doesn’t always work—and the fear and distress never go away completely—but worrying about what could be isn’t going to change what will be.”

**LUNGevity, an organization that allows lung cancer patients to connect, share support, and learn about the latest treatments and more.**

“There is nothing like connecting with someone else in the trenches because these friendships can help alleviate anxiety and loneliness. From the outside looking in, no one can understand—and from the inside looking out, it can’t be explained.”

**Connect with survivors.**

“I work at a camp every summer in Culver, IN, which is where I went to camp as a kid,” says Jill. “When I was 13, my dad died of lung cancer in the spring, so I couldn't wait to get back to Culver where I could escape reality and pretend my life was normal for a few months. I call it ‘Gumdrop and Lollipop Land!’ Today, 34 years later, it hasn’t changed. When I’m at camp, I get a ‘breather’ from lung cancer—I’m able to take a break and recharge, both physically and emotionally. I know everyone can’t go to camp, but they can find an hour each day or several times a week to escape.”

**“We’re not just survivors—we’re thrivers!”**

Jill, Matt and Sarah offer the strategies that help them defy advanced lung cancer and keep going strong! —BY AMY CAPETTA
“Find the encouragement around you”

Sarah Kilgore, Raybon, GA
Diagnosed with stage IV lung cancer in 2016

Harness the power of positive thinking. “I don’t push religion on people, but I go to church, I pray and I fill my mind with positive thoughts,” says Sarah. “One message that I tell myself—and others—is: I FEEL GOOD! When people ask me how I’m doing, if I say, ‘Well, I feel bad today,’ I won’t feel well at all. Even on those days when I don’t feel great, I say it anyway. I really believe that your mind can change the chemicals in your body.”

Tape important conversations. “I record all of my sessions with doctors,” says Sarah. “I started doing this so I didn’t have to repeat everything that was said during the appointment to my family—I could just send them the recordings. Then I realized it was also an easier method for me because then I didn’t have to take notes or rely on my memory. Before the appointment, I always let the doctors know that I’ll be recording them.”

Create your personal support network. “I can’t relate to most people in the support groups because they’re usually in their 60s and 70s,” explains 25-year-old Sarah. “So I purposely surround myself with loving, positive people, which include my family, my in-laws—I have the best in-laws ever!—my church family, and my friends. And then there’s my husband, Jacob—he’s my go-to; he’s my backbone. When we’ve gotten unexpected results from a PET scan, he has said, ‘You can take one day to cry and have a pity party, then you have to pick yourself up and keep going!’ His encouraging words make me even stronger.”

Let go and look forward. “Getting this diagnosis has definitely been a life-changing experience for me and my husband,” confesses Sarah. “It has motivated me to become a better human being. I’m now a ‘water under the bridge’-type person because I’ve learned being angry really drains you. In fact, it’s actually easier to be nicer to people and to be happy! Also, having lung cancer has made me want to do more in the world. I want to go to school, work in a lab and become a scientist. No one knows when their time is coming, and I feel like I’m going to beat this thing and make a difference!”

“Adopt the right mindset”

Matt Ellefson, Sioux Falls, SD
Diagnosed with stage IV lung cancer in 2009

Get into the driver’s seat. “The separation between short-term and long-term survivors is the preparation they’re willing to put in to the fight of their life,” says Matt. “Survivors who anticipate great outcomes prepare for great outcomes. I know first-hand—over the last eight years, I’ve had six recurrences of cancer, all of which have been treated successfully. That is why I founded SURVIVEiT.org, which provides anyone affected by cancer with immediate free access to a global community of survivors, doctors and experts. In other words, we are survivors helping patients.”

Ask the “right” questions. “It is crucial to understand your diagnosis, your treatment options, and what you need to do next,” emphasizes Matt. “In the Resource Library section on my site, I advise downloading the ‘21 questions to ask my oncologist’ page.” (A few of those questions include: Are there any clinical trials or immunotherapies I should consider? What cancer or academic center is doing the most research on my type of cancer?) “Also, ask your oncologist to send your biopsy tissue to Foundation Medicine for genomic sequencing,” he suggests. “Then take these results to an academic research cancer center to receive a qualified second opinion.”
The support you need is there for the taking!

Karen Loss and Donna Fernandez say immunotherapy is helping them live with stage IV non-small cell lung cancer—and support is helping them feel unstoppable. Here, they share their top tips for getting the practical help and TLC that can keep you going!

Keep doing the things you love. A favorite pastime for Donna is taking her dogs to agility training (think obstacle course for dogs). When treatments made Donna too weak to drive to agility practice, “My husband, Robert, would drive me to the field, then sit in the car and wait for me. Even though he didn’t think that exhausting all my energies with running agility was smart, he knew how important it was to me…I do think staying active doing what I love has helped me fight my cancer, physically and emotionally.”

Lean on your “listeners.” When Karen is feeling especially stressed out, she calls on one of her sisters. “Basically, people can’t eliminate the problem, but by simply listening, they can allow you to vent and this is important.”

Invite help—even from miles away. While Robert is Donna’s primary source of emotional support, “I am very fortunate to have other friends and family who step up for me,” she says—including her mom, her son and his fiancée, cousins and friends. In fact, one cousin is “always first to donate when I am raising money for lung cancer research and the first to forward along information that I post on Facebook about lung cancer. She lives about 300 miles away, but I know she’s there for me.”

Turn to your care center. “I have had my cancer clinic’s insurance specialist find out whether my insurer would cover a blood biopsy,” says Karen. “She also contacted the pharmaceutical company that makes one of my expensive drugs to find out about any programs that can help defray the cost.”

Draw strength from your faith. “I have a very positive attitude about having cancer and here’s why: I tell everyone I am in a win-win situation,” says Donna. “I am quite happy being alive. I love being here. But, when I take my last breath here on earth, I believe I will wake up in heaven on streets of gold, in my father’s presence. Wow! I don’t worry before scans. I don’t worry when I am told my tumors have grown. I don’t worry. My belief is that God has this.”

Reach out to your nurses. “I’m now in a clinical trial, and if I have any questions or concerns—especially about side effects—I ask my clinical trial nurse,” says Karen. “Before joining the trial, my clinic assigned a nurse navigator to my case, and I still turn to her. She and my trial nurse are very responsive to email or voicemail questions.”

Recognize the blessings. “I have met some of the most fabulous people ever because of my lung cancer,” says Donna, who occasionally lunches with friends she’s made at events for LUNGevity, an organization that helps connect lung cancer patients. “We have to me to a fabulous informal support group! People think I’m crazy. I wouldn’t have wished to have cancer, but I wouldn’t trade the experiences it has brought me, or the people it has brought into my life.”

Go “social.” “I belong to a few online lung cancer patient groups where people get emotional support and first-hand answers from others who have been down the same path,” says Karen. “I think it is good for patients to interact in this way because we understand one another’s circumstances in ways that others simply can’t.”

Her go-to social networks include:
- The American Lung Association/Inspire Lung Cancer group; the Lung Cancer Awareness group on Facebook; and the LCSM (Lung Cancer Social Media) Tweet-chats that happen every other Thursday.
- The Lung Cancer Awareness Group on Facebook; and the LCSM (Lung Cancer Social Media) Tweet-chats that happen every other Thursday.
- Find your touchstone. “When I was so weak and so sick from chemo early on, there were times when I wondered if it was worth it to keep fighting,” says Donna. “Then, I’d look at my two dogs and know that I had to keep going! My Sheltie would lie on my chest and I could imagine the tumors being drawn out by his body heat.”

Reach out. When Karen was on a chemo cocktail that made driving impossible, she called her pastor, who signed her up with a program that provided volunteers to drive her to and from her infusions.

Let the love come to you. Often, there’s no need to even ask for help. When the agility instructor who works with Donna’s dogs heard she needed to raise her electrolytes, he showed up one day with bags of groceries! “He researched what foods help raise electrolytes, went shopping for them and then drove an hour to bring them to me. He also bought me every kind of sports drink known to man. And, he ‘reminded’ me at every opportunity that I needed to be drinking and eating foods to get those electrolytes up. It worked. They were normal at my next blood test!”

Broadcast your news. “On the day I was diagnosed, I made a conscious decision to share my cancer journey with others,” says Karen. “I began by sending emails to a large group of friends and family who were in my personal address book.” Nearly five years later, Karen still relies on her email loop.
For caregivers: How to be there

Finding the balance between providing care and not pushing too hard can be tricky. But Robert Fernandez, who’s been at wife Donna’s side throughout her cancer journey, has worked it out. Read on for his strategies!

Foster joy. A priority for Robert is enabling Donna to enjoy her favorite hobby: “I make sure she has the resources needed to go to her agility lessons and trials,” he says. “I always want to make her happy, and agility makes her happy!”

Respect your loved one’s decisions. At medical appointments, “be there, but don’t smother. Listen and don’t judge. Don’t offer too many unsolicited opinions.” That suits Donna: “He knows I do a lot of research and stay pretty much on top of things,” she says. “He supports whatever plan of action I decide on.”

Be present for important treatment conversations. “If I can’t make it to an appointment, Donna and I discuss what happened in detail and talk about what next steps would be. But when important conversations are going to take place, I make it a point to be there.”

Keep your health top of mind. “You can’t do much for your loved one if you get sick or burn yourself out,” says Robert. “Keep up with your own medical needs. Eat right. Exercise. And, take a break from cancer. I retreat upstairs to play on my computer, watch TV or talk to friends.”

Have a communication strategy. “When Donna was first diagnosed, we made the decision not to worry our family (Donna’s mom and our son). We have never strayed from that decision,” he adds. “So, we let the family know that there are new challenges, but we always want them to know that we are doing what needs to be done and that there’s no need to worry.”

Start day one with hope from the American Lung Association. Find credible information and resources online, learn about clinical trials in your area, and talk to lung cancer experts that understand your unique lung cancer journey.

Every lung cancer patient needs a guide. Trust us to be yours.

Call 1-844-ALA-LUNG to talk to a lung cancer expert today, or visit Lung.org/lung-cancer for up-to-date information and resources.
Managing advanced lung cancer can be challenging. Fill out this tool and share it with your healthcare team to make sure you’re doing all you can to thrive.

How have you been feeling?

Check the box next to any symptoms or side effects you’re currently experiencing:

- Anemia
- Appetite changes; difficulty eating
- Bleeding
- Breathing difficulties; shortness of breath
- Cloudy thinking
- Constipation
- Coughing
- Depression, anxiety
- Diarrhea
- Fatigue
- Flu-like symptoms
- Hair loss
- Headache
- Hot flashes
- Itch
- Memory loss
- Mouth sores
- Muscle weakness
- Nausea and vomiting
- Neuropathy
- Pain (fill out next page)
- Sexual changes
- Skin and nail changes
- Sore throat
- Trouble swallowing
- Urinary and bladder changes
- Weight loss or gain
- Other __________________

Talk about any pain you may have:

- Where it hurts: ____________________________________________________________
- What time of day pain occurs: ______________________________________________
- How many days of the week pain occurs: _______________________________________
- How long pain lasts (e.g., one hour, four hours, all day): _______________________
- How severe the pain is, on a scale from 0 to 10, with 0 as no pain and 10 as the worst pain possible:
- What the pain feels like (e.g., aching, burning, throbbing, stabbing, pressure):
- What makes the pain worse? _________________________________________________
- What makes the pain better? ________________________________________________
- How does the pain affect your life? (your sleep, appetite, activities—the more specific you can be, the better): __________________________
- What medications (and dosages) you’ve used, and how they have helped: ________

Important! Report any pain promptly to your care team.

Do you need palliative care?

Palliative care is supportive care, and includes treatments designed to relieve difficult symptoms and improve your quality of life. Your doctor may discuss palliative treatment with you if you have:

- Fluid buildup in the chest, outside the lungs
- Fluid buildup around the heart
- A tumor that has blocked an airway
- Nausea, pain, depression, anxiety and more

Are you experiencing depression or anxiety? Your doctor needs to know! Mood problems can be treated.
Questions to ask your care team

Getting the answers can help you monitor your treatment and take charge of the next steps.

1. What are the results of my latest tests and scans, and what do they indicate about my current treatment?

________________________________________________________________________________________

________________________________________________________________________________________

2. Do you recommend a different treatment strategy at this time? If so, how does it work and how can it help me?

________________________________________________________________________________________

________________________________________________________________________________________

3. How is this treatment given? How long will I need to take it?

________________________________________________________________________________________

4. How will we know if I am responding to this treatment? What tests are performed to monitor me and how often will I need them performed?

________________________________________________________________________________________

5. Will I be able to work during treatment?

________________________________________________________________________________________

6. What are the side effects I might feel? How can they be avoided?

________________________________________________________________________________________

7. Are there any side effects that I should report to you immediately?

________________________________________________________________________________________

8. What should I know about immunotherapy? Is it an option for me?

________________________________________________________________________________________

9. What can I do on my own to avoid complications and feel my best?

________________________________________________________________________________________

10. Is there a clinical trial that can help me? What are the pros and cons of participating in a trial?

________________________________________________________________________________________

Always tell your doctor about…any other health problems you may have, plus all prescription and non-prescription medicines, vitamins and herbal supplements you take.