



Choices & Hope

My Cancer Journey

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Ed Levitt

"My name is Ed Levitt. I am a Stage IV lung cancer survivor. Stage IV lung cancer and survivor in the same breath -- now that's an oxymoron." --That's me, speaking to a group of lung cancer survivors at "Celebrating Life" conference in Atlanta Georgia..

I DO have advanced Stage 4 Lung Cancer. To me it is just another direction in my life. It will only win if I let it. I believe ATTITUDE is everything.

Prior to being diagnosed with Stage IV lung cancer six years in January I enjoyed a full and productive life. My wife and I were making plans for our retirement. It was very important to us because my work kept me on the road 27 days a month for 20 plus years. I even won an award for the most traveled person in company. I lived to work, some would say I was a workaholic. I had a wonderful career at two major USA corporations as an international speaker and motivator. I spoke to major corporations and groups from 5 to 5,000. It was an exciting and demanding life. I never wanted to stop. To be honest I did not think I could stop. I was driven. My day always started at 4:30 a.m. unless I was catching a plane and then it could be an all-nighter. It really didn't matter as it was my life. It is important to note that I always worked hard and never found time to play or get sick.

I promised my wife we were going to make up for never being together when I retired. We made great plans and were very excited. Unfortunately, somebody upstairs did not listen! When I was making these great plans because at the most inopportune time the stock market crashed and our plans had to be put on hold until I reached 65 or we could save enough to get our life back on track. Was it bad? That's an understatement. Initially it was devastating. As I am sure it was for many who are reading my story!

My Cancer Journey:

It was the last week in January 2003. My day started out great. I was psyched. My alarm went off, three hours in the gym, ran 44 flights of stairs and I was on my way to Las Vegas for our annual convention. I was getting off of the plane in Vegas and I started walking from the plane to baggage claim. After a few minutes I developed a severe pain in my right leg in the groin area. I was used to aches and pains because I exercised so much and, yes, I was getting older. So I ignored it. As the days went on the pain grew worse, I started to limp. Towards the end of the convention I was getting dressed but could not raise my leg to put my pants

November is Lung Cancer Awareness Month!

on. I spent 40 minutes sitting on the floor of my hotel bathroom trying to put my pants on. The pain was getting bad, very bad.

After returning home my wife insisted that I see the doctor. I believe that because of my lifestyle, the doctor thought I had some inflammation due to over exercise and prescribed some anti-inflammatory medication. The doctor said I was over 60, and my workout schedule was excessive, if there was no change in about 2 weeks she needed to see me. Well, in one week I revisited the doctor with a hard lump in the right groin. She immediately gave me a thorough examination and this time I was given a chest x-ray, blood tests, a CAT scan, MRI, and a bone scan.

The X-ray had a spot on it, so they did it again. Yep, spot still there. The bone scan showed tumors on my spine, ribs, neck, collar bone and more. The CT scan showed spots on my lung and both adrenal glands with large tumors. I was diagnosed with stage IV lung cancer!

After three months of chemotherapy, I had a CAT scan which showed my cancer had spread almost 40 tumors in all. I thought I was out of luck, but then I had radiation and started on the "Fast Track" drug Iressa. In three months I had another scan and this time my cancer was reduced by 70%. And the two large tumors in my adrenal glands were gone.

OH, I forgot I also developed a 2nd primary cancer "Bladder" cancer!

My doctors told me because I was in such good shape for my age that I was still alive to fight the disease. They told me to keep moving, it will help me stay alive!

Lung cancer changed my life! As a result of my journey, I offer my speaking skills to any group that will listen. I started Lung Cancer Alliance of Georgia. I became the Georgia lead advocate and at the time of this writing our group works collaboratively with the hospitals and oncology specialists in Georgia. We are here to make a difference. That's right, make a difference for lung cancer!!!

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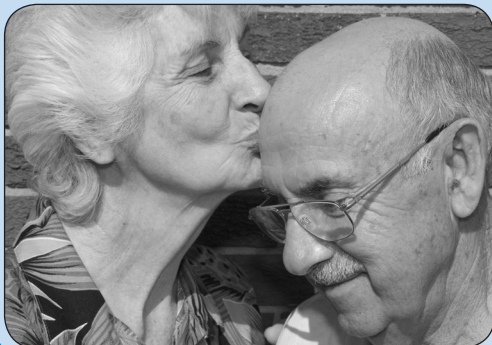
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Mission: The Caring Ambassadors Program mission is to help improve the lives of those affected by lung cancer through advocacy, information, and support.



From the Program Director

Dear All,

November, Lung Cancer Awareness Month, is the greatest single opportunity each year to influence public awareness about lung cancer. Throughout November, organizations involved in lung cancer advocacy are hosting events throughout the Country.

This year, we are hosting our 1st Annual CAP Lung Cancer Benefit Bowl-A-Thon in Vancouver, WA. Hundreds of bowlers are lacing up their shoes and bowling in an effort to increase awareness about the issues surrounding a lung cancer diagnosis. The benefit will help CAP continue to provide our programs and services to increased numbers of newly diagnosed lung cancer patients and their loved ones upon diagnosis. There is hope for all people facing lung cancer and CAP is here to help!

In August, CAP hosted a booth at the 13th World Conference on Lung Cancer sponsored by the International Association for the Study of Lung Cancer (IASLC) in San Francisco. Lung cancer professionals from throughout the world shared the most up-to-date information regarding the science and advances in the treatment of lung cancer. Researchers are making progress unraveling the complexities of lung cancer – with each new discovery, we come closer to the day when lung cancer will no longer be the threat it is today.

While in San Francisco, CAP participated in the Lung Cancer Action Network (LungCAN) face-to-face meeting. LungCAN is a group of 27 lung cancer advocacy organizations who have come together to raise awareness in the general population of the realities of lung cancer with the intention of increasing funding for detecting, treating and curing the disease. Our goal is to increase the five year survival rate and decrease the morbidity of lung cancer worldwide.

All in attendance agreed the negative stigma and blame associated with lung cancer is a major problem. It is crucially important for us to involve and organize many more people in the lung cancer advocacy movement.

LungCAN has developed a joint website in which we can build upon each other's strengths and essentially be a clearing house for information and support for the lung cancer community. Please visit the site at www.LungCAN.org.

During September, CAP leadership visited the Oregon Health Sciences University Radiation Oncology Department. Dr. Charles Thomas gave a tour of the facility; including a wonderful tram ride! Dr. Biquart, Dr. Thomas and Dr. Holland submitted an article "The Role of Radiation Therapy in the Treatment of Lung Cancer" for this issue of *Choices & Hope*. Thank you for your generous commitment of time, we look forward to partnering with OHSU in the future.

Progress is happening in the lung cancer field and there is HOPE for those living with the disease!

With Best Wishes for Your Health,

Cindy Langhorne

Cindy Langhorne
Program Director

LungCancerCAP.org

Within CAP Lung Cancer

Ways to Give!

NOVEMBER IS LUNG CANCER AWARENESS MONTH

More than 219,000 American men and women will be newly diagnosed with lung cancer this year and tragically, approximately 159,000 will die of the disease. November is Lung Cancer Awareness Month and we encourage you to join with us in our efforts to raise lung cancer awareness, compassion, and help reduce the stigma associated with the disease.

CAP Lung Cancer is honored to be serving the lung cancer community through advocacy, information and support. Each and every contribution is important to the organization – please make your donation today! We are genuinely grateful for your support.

Helping the Caring Ambassadors Lung Cancer Program is easier than ever. The CAP Lung Cancer Program has developed a special donation opportunity for you!

A CAP Celebration Gift celebrates milestones in a loved one's life — a birthday, anniversary, graduation, wedding, or another cause for celebration. A CAP Celebration Gift is also a meaningful way to pay tribute to those living with lung cancer as they mark personal milestones on their journey.

When you request a CAP Celebration Gift or CAP Gift in Memory online, we will send a personalized card to the person or family you are honoring to let them know of your gift. Your secure online donation will help the Caring Ambassadors Program continue our efforts to improve the lives of people affected by lung cancer.

*Make someone's day by sending them a
Caring Ambassadors Card today!*

LungCancerCAP.org

Please help the Caring Ambassadors Lung Cancer Program continue serving the lung cancer community. As a public charity, we rely on your help and support to continue providing services to people living with lung cancer and their loved ones.

Caring Ambassadors Program Online

- *State of the art information about lung cancer diagnosis, treatment and supportive care*
 - *Choices & Hope newsletter*
 - *Weekly E-News*
- *Lung Cancer Medical Writers' Circle*
- *Monthly lung cancer literature review*
- *Pharmaceutical patient assistance programs*
 - *Lung cancer awareness activities*
 - *Community outreach and support*

Sign-Up at LungCancerCAP.org



**Would you like to contribute to
the Writers' Circle?**

Email Info@LungCancerCAP.org

*Together we are making a difference in the lives
of people affected by lung cancer.*

Caring Connections

Twice Betrayed: Living With Lung Cancer and Dealing With Stigma

Susan Hedlund, MSW, LCSW

For many people dealing with a diagnosis of cancer, a myriad of complex emotions may occur. Initially, shock, fear, and disbelief may be the overwhelming emotional responses to a new diagnosis. These are often replaced by feelings of grief and sadness, as one attempts to deal with the challenges of treatment and the impact on one's life style. Fortunately, many people are, in time, able to navigate the challenges of cancer and treatment, and find a new balance in their lives.

Some cancer diagnoses, however, are more difficult to deal with than others. Depending on the type of cancer and the stage of disease, there may be fewer treatment options available, and for some, the likelihood of long-term survival may be more remote.

For people diagnosed with lung cancer, numerous challenges exist. Depending on the stage of the cancer at diagnosis, treatment options may offer the hope for long-term recovery. However, the overall survival rate for all lung cancers remains at 15% for 5 year survival. This is significantly lower than other cancers. For example, there is close to a 100% - 5 year survival rate for men diagnosed with prostate cancer; an 89%-5 year survival rate for women diagnosed with breast cancer; and a 65% - 5 year survival rate for people diagnosed with colon cancer. Three times as many men will die of lung cancer than of prostate cancer, and twice as many women will die of lung cancer than of other cancers. Lung cancer is the leading cause of death of all cancers in all ethnic groups. Lung cancer accounts for 1 in 3 cancer related deaths, and approximately 152,000 people are expected to die of lung cancer in the U.S. in 2009.

As if this news is not difficult enough, many people diagnosed with lung cancer face an additional burden of feeling "blamed" for their disease. Whether one has a history of having smoked or not, most studies report that people with lung cancer feel stigmatized for having the disease. While 87% of lung cancers may be related to a smoking history, other lung cancers are caused by environmental causes, genetics, or age. Also, reviewing the cultural aspects of the United States in the last 60 years, we know that the risks of smoking were not previously fully understood, and that both the media and tobacco companies promoted the "glamour" of smoking. The post World War II era saw smoking as a part of one's affluent lifestyle. We also now have a better understanding of addictions. Tobacco addiction is a very difficult addiction to overcome. Sheer will-power alone may not be enough to overcome tobacco addiction.

Still, whether one has smoked or not, no one deserves or asks to get lung cancer. The impact of stigma has far reaching effects. British researchers interviewed 45 lung cancer patients between the ages of 40 and 90. Most of the patients felt that others were holding them responsible for getting sick because of the link between smoking and lung cancer. But even lung cancer patients who never smoked, or who quit decades before, felt this stigma, University of Oxford researchers reported. The negative feelings caused some patients to conceal their illness, which hampered their ability to get support from others. Others in the study worried about being denied care because of the perception that they caused their own illness.

Many people with cancer feel isolated and some feel shame, however these feelings are stronger among people with lung cancer. "It is a special stigma. The whole thing has been tainted by the smoking thing", says Jimmie Holland, MD, professor and vice chair of psychiatry at Memorial-Sloan Kettering Cancer Center in New York.

Other effects from this stigma have to do with support and research. Treatment and support services lag behind those of many other cancers. In 2007 the National Institutes of Health provided \$572.4 million for breast cancer research, but only \$226.9 million for research on lung cancer, although lung cancer remains the number one killer in the United States. Despite lung cancer causing one in three cancer deaths, lung cancer received less than 5% of the National Cancer Institute budget in 2007. Lung cancer received no funding from the Department of Defense or Centers for Disease Control, both of which funded breast cancer research at \$2.07 billion and \$201 million respectively in 2007. The reason that so much more is known about breast cancer and why treatment has been so effective is largely because of the money put into it and the enormous advocacy efforts behind breast cancer awareness and research.

Gregory Otterson, MD, medical director of Thoracic Oncology at Ohio State University Comprehensive Cancer Center-Arthur G. James Cancer Hospital states: "With lung cancer, the stigma persists, and there is the perception that you 'brought this on yourself'. That same argument was made about HIV, and it's now obvious that it is inappropriate. Look what happened with AIDs".

No One Deserves Lung Cancer!

Twice Betrayed (continued)

Susan Sontag, author, in her books *Illness as Metaphor* (1977) and *Illness as Metaphor and AIDS and Its Metaphors* (2001) writes about the assumptions and fantasies attached to diseases that we have yet to understand. She references diseases such as cancer, AIDS, and in earlier times, tuberculosis and epilepsy, and describes how people often responded with fear about things we had yet to fully understand. She contends that illness is not a metaphor, and that the most truthful way of regarding illness – and the healthiest way of being ill- is to resist such metaphoric thinking. “ Nothing is more punitive than to give a disease a meaning- being invariably a moralistic one. Any disease whose causality is murky, and for which treatment is ineffectual, tends to be awash in significance.” (Sontag, 2001)

It is important to remember that the stigma associated with all cancers has lessened considerably in the past 40 years, as we have come to understand and more effectively treat, many cancers. We now talk about cancer openly, versus keeping a “conspiracy of silence”. In most cases, we no longer isolate the people who have the disease. While lung cancer unfortunately continues to carry some stigma, that too, is changing, as the medical and lay public have more information, greater awareness, and more exposure to the disease. Advocacy efforts and support services are growing. The visibility of people with lung cancer who are willing to publicly discuss it and advocate on behalf of more research, also helps.

Ask for help from your medical providers. An oncology social worker in your hospital or clinic can tell you about local support groups and educational resources. If you are someone who is currently smoking, and you would like to try to quit, ask about smoking cessation resources in your area. Remember that you are not alone.

If you are a family member or friend of someone with lung cancer, try to remember that lung cancer, like any cancer, is a challenging disease with many psychological and social challenges. Your loved one needs your understanding and support. Ask how you can best help them during this challenging time. Sometimes the more practical things can be most helpful. Can you bring a meal, or transport your friend to doctor’s appointment? Do the children need extra help? Many things, great and small, can help the person with cancer.

In conclusion, lung cancer continues to be a serious, life-threatening illness. Additionally, there continues to be stigma about the disease, and toward the people who have it.

It will be important to continue advocacy efforts and awareness about the disease, the needs of patients, and the need for further research. People dealing with lung cancer need and deserve support and understanding. Again, if you are a patient, please remember that you are not alone. There is help available.

Susan Hedlund, LCSW, has been a social worker in the health care field for twenty eight years and has extensive experience working with individuals and families facing life threatening illness and loss. She is currently the Director of Social Services for Hospice and Palliative Care of Washington County in Portland Oregon, and is on the faculty of the School of Medicine at Oregon Health & Sciences University, as well as the Graduate School of Social Work at Portland State University. She was previously the Director of Counseling at Cancer Care Resources, and the Clinical Manager of Social Work at OHSU.



She is a past president of the National Association of Oncology Social Work, and received their Leadership Award in 1999, and the national American Cancer Society Quality of Life Award in 2009. She received the Compassion Award from Breast Friends, a breast cancer advocacy group in 2009. She speaks nationally and internationally, and publishes on topics related to coping with illness, end of life issues, and loss. Additionally she served on the Oregon State Task Force to Improve the Care of Terminally Ill Oregonians, the Oregon Partnership for Cancer Control, is a Senior Scholar for the Center for Ethics at OHSU and co-founded the Well Arts Institute, a non-profit program for arts in health care settings. She is the past chair of the Health Specialty Practice Section for NASW nationally.

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1st Annual CAP Lung Cancer Benefit Bowl-A-Thon

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From the Experts

The Role of Radiation Therapy in the Treatment of Lung Cancer

Celine Bicquart, MD

Co-Authors Charles R. Thomas, Jr., MD, Professor & Chair and John Holland, MD, Associate Professor
Department of Radiation Oncology, Oregon Health Sciences University

The treatment of lung cancer varies greatly by the type and stage of the tumor, as well as the overall health of the patient. As 80% of lung cancers are non-small in histology, this discussion will focus on the role of radiation in treating NSCLC (non-small cell lung cancer).

In early stage lung cancers in which the tumor is confined to the lung, the only therapy required may be surgery to remove the tumor. More often however, at the time of diagnosis, the tumor has spread to regional (nearby) lymph nodes. If multiple lymph nodes are involved, or if the lymph nodes are bulky, surgery may not be appropriate. In this case, definitive (curative) therapy is usually a combination of chemotherapy and radiation.

Radiation is a therapy which is local in nature. Whereas chemotherapy circulates throughout the body, radiation works where it is aimed. Radiation causes damage in the DNA (genetic material) of the tumor cells. This damage accumulates throughout the course of treatment, ending with death in the tumor cells. Patients often wonder why treatment occurs daily over a series of weeks. We take advantage of normal cell and tumor cell radiobiology (actions of biological cells to radiation). Normal cells repair sublethal (non-terminal) DNA damage, or heal everyday following treatment. Tumors don't repair damage as well, leading to their eventual death. Although it's inconvenient, by fractionating (dividing treatment over a course of weeks), we can deliver a maximum amount of radiation to

kill the tumor, while at the same time, allowing normal cells to heal and tolerate treatment as best as possible.

The first step in planning for radiation is CT simulation. During this process, the radiation oncologist will obtain a CT scan in the department. This scan is done in the exact position that treatment takes place daily; "simulating" the activity of the radiation beams and the effects on the tumor and surrounding normal tissue. It is on this scan that the tumor and involved lymph nodes are drawn, as well as all the normal surrounding organs. Often, additional imaging is used to help create the best possible plan. PET/CT simulation is a treatment planning session in which a PET scan is also done to show metabolic activity present in the body. PET scans involve injection of a radioisotope labeled sugar; the sugar localizes to sites in the body that are metabolically active, including tumor which is active due to its rapid cell division. In formulating a treatment plan for lung tumors, special care is taken to limit radiation dose to the uninvolved lungs, heart, esophagus, and spinal cord. There are different techniques of planning radiation. 3D-conformal planning is a type of forward planning. Target volumes are first contoured (drawn out), beams are placed, and a plan is generated. It is then modified to meet dose objectives. Intensity modulated radiation therapy (IMRT) is a different technique that is employed when a more conformal (contour-fitting) delivery is desired. Changes in the intensity of the beam during treatment are accomplished through the use of multi-leaf collimators (MLCs). These are small leaves that shield or block radiation and can shift in and out to shape each field, resulting



The Caring Ambassadors Program leadership visited the Department of Radiation Medicine at Oregon Health Sciences University, Portland, OR on September 18, 2009. Ms. Langhorne, Ms. Lorren D. Sandt (Exec. Director), along with Mrs. Roberta "Birdie" Urban, Lung Cancer Survivor and CAP Board of Directors member along with Stan Urban, are pictured here with Dr. Charles Thomas.

From the Experts *(continued...)*

in dose that wraps nicely around the target, while sparing normal structures as much as possible. IMRT uses inverse planning- target objectives which are set at the beginning, and the radiation planning software designs a plan to meet these objectives. After an optimal plan is developed, treatments start and continue for a series of weeks.

Each treatment lasts approximately 20-25 minutes. The first few weeks of radiation are relatively easy; however, side effects gradually set in as the radiation dose to normal tissue accumulates over time. Radiation for lung cancer most often causes fatigue, redness of skin, nausea/vomiting, odynophagia (pain with swallowing), anorexia (loss of appetite), and weight loss. Those patients that receive concurrent (at the same) chemotherapy often note more pronounced and/or additional side effects e.g.- decreased blood counts and are at higher risk for infection.

For patients with a lung tumor and involved lymph nodes, one possible definitive treatment consists of radiation and chemotherapy given together for approximately 6.5 weeks. If there is only a tumor with no involved lymph nodes, surgery, if the patient is a candidate, is usually the best option. Sometimes patients with small, resectable tumors are not good candidates for surgery because of underlying illnesses like heart or lung disease. If the patient is not deemed a surgical candidate, stereotactic body radiotherapy (SBRT) is a good alternative. SBRT is reserved for small isolated tumors, and is a technique of delivering very high dose to this volume in just a few (3-5) fractions (treatments). Delivering such a high dose with each fraction requires precision, which is accomplished through 4-D simulation. This simulation takes into account not only the position of the tumor in the lung, but also its movement during breathing. Given that these treatments require such precision, patients are immobilized in a body-fix. This is a giant blue bean-bag that is shaped around the patient. Each body-fix is custom-made for each patient and each SBRT treatment takes 45 minutes- 1 hour.

Patients that have surgery for lung cancer do not frequently receive post-operative (after surgery) radiation. Indications for post-operative radiation include a positive margin (tumor at the edge of the specimen) or many involved lymph nodes in the middle of the chest.¹

In tumors involving the top of the lung (superior sulcus tumors), treatment is often multi-modal, involving neoadjuvant (before surgery) chemotherapy and radiation, followed by surgery. In this case, we typically treat with chemotherapy and daily radiation fractions over 4-5 weeks, with surgery to follow 4-6 weeks later.²


There are clinical situations in which patients unfortunately present with metastatic cancer at the time of diagnosis. In these cases, there is not a role for definitive radiotherapy. Radiation can however, be given to palliate (relieve) local symptoms, e.g- cough, chest pain, hemoptysis (coughing up blood), or dyspnea (pain with breathing).^{3 4} Radiation is typically given daily over a series of 10 treatments to symptomatic patients. There is no benefit to giving immediate palliative radiotherapy to asymptomatic patients.⁵

Lung cancer is best treated with a multi-disciplinary approach. Radiation has a major role in the treatment of various stages of lung cancer. Technological improvements in the last decade have enabled radiation oncologists today to deliver more precise treatments than ever.

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Celine Bicquart, MD is a resident physician in Radiation Medicine at Oregon Health Sciences University in Portland, Oregon. Her research interests are in breast and GI malignancies, specifically-pancreatic cancer. She is the lead author on a retrospective study on the OHSU experience of resected pancreatic adenocarcinomas detailing the effect of chemoradiation on overall survival. She is currently looking at outcomes of breast cancer patients treated with partial breast radiation: conformal 3D radiation vs. interstitial brachtherapy vs. mammosite.





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The goals of the CAP Lung Cancer Program are to:

Improve the quality of life of people living with lung cancer and their families through information and support

Provide state-of-the-art information about lung cancer treatment options to patients and their families

Increase lung cancer awareness and advocate for increased prominence of lung cancer on local, state and national public health agendas

Motivate people and groups concerned about lung cancer to work together for the good of all persons affected by the disease

Choices & Hope

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