



LUNG CANCER CANADA

Awareness. Support. Education.

**Lung Cancer
Connection**

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Assessing Symptoms with ESAS – Living Better Despite Lung Cancer

The ESAS, Edmonton Symptom Assessment System, is a symptom screening tool that assesses the severity and distress of the following symptoms: pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, shortness of breath and overall sense of well-being.

For a patient diagnosed with any form of cancer, oncology teams appropriately focus much of their efforts on treatments directly targeting tumours and cancer cells. In the past few years, health care overall has evolved to become much more “patient centred” with greater emphasis placed on addressing subjective experiential needs of patients.

In the context of cancer care, in addition to individualized treatment plans an example of “patient centredness” is a focus on the type and severity of symptoms and their impact on the patient’s life. Strong evidence now exists demonstrating a direct correlation between how well symptoms are managed and levels of distress, overall quality of life and even survival.

The vast majority of patients who are living with cancer experience a range of symptoms at some point during the course of their illnesses, with many reporting multiple symptoms simultaneously. In the clinic or outpatient setting, the average number of distressing symptoms for patients is 5 whereas this number increases to 10 among patients in the acute care hospital or inpatient setting. Symptoms represent a direct effect of the cancer, a side effect of the many treatments, a concurrent comorbid illnesses or any combination of the three. Although variable among different sub-populations, the most common symptoms for cancer patients are fatigue, poor appetite and pain.

Compared to those with other types, lung cancer patients have been found to experience a greater number of both symptoms and distress in the course of their illness. The diagnosis of lung cancer is often made in patients following presentation with various symptoms. If these symptoms are not managed well, patients are more likely to have higher distress levels throughout the course of the disease. This evidence has resulted in the recommendation that clinicians caring for lung cancer patients assess for and manage any symptom from the moment the patient is first diagnosed.

Given the time limitations oncology teams face due to extraordinarily high patient volumes, several tools have

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been developed to screen for the presence of symptoms. Certain tools additionally allow patients to communicate the associated severity.

An effective screening tool is one that:

- patients can complete with ease
- addresses a broad range of symptoms
- has patient-related data which can be interpreted rapidly so that individuals who require a more formal assessment are identified.

Developed with these key qualities in mind, the Edmonton Symptom Assessment System (ESAS) addresses the following symptoms:

- pain
- nausea
- anxiety
- appetite
- overall sense of well-being
- tiredness
- depression
- drowsiness
- shortness of breath

For each of the above, patients are instructed to choose a number between 0 and 10 that best represents how they would rate severity of the symptom, with “10” being the worst possible and “0” being the absence of the symptom all together.

The ESAS design provides a general quantification of symptom severity, which can be used to identify patients requiring further dialogue and assessment to better understand their experience and initiate targeted interventions. This tool, used in many clinical settings internationally, has been shown to be valid and reliable.

Because symptoms in cancer patients are dynamic and fluctuate over time, they should be routinely monitored by clinicians, regardless of the disease trajectory. This is particularly true for those patients living with lung cancer. Routine screening for symptom severity using a simple but informative tool like ESAS is quickly becoming an essential element of standard cancer care.

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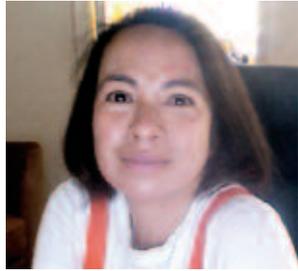
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Lung Cancer – A Patient’s Journey: Jennifer Fong, Alberta



Jennifer is 45, a wife, young mother of two wonderful boys, has never smoked, and is living with lung cancer.

Her story is a case study in how perseverance, determination and hope can make a difference in a life threatened by serious disease.

Jennifer was diagnosed with the disease in January 2010. Her symptoms began with a cough. But it was flu season so she wasn’t unduly concerned until she saw blood in her sputum. The cough disappeared, nevertheless, Jennifer followed up with a visit to her family doctor for a full physical. When she mentioned the blood, the diligent physician immediately arranged for a chest x-ray. The x-ray revealed a 4 cm tumour in the upper right lobe. A referral and further tests at the Tom Baker Cancer Centre, Calgary, confirmed the tumour had metastasized. Her surgeon told Jennifer the tumour was not surgically resectable. What to do?

Jennifer sat down with her radiation and medical oncologists to set out a treatment plan. At the same time, the gravity of her situation led her to seek other opinions. She consulted specialists in Toronto and New York, who confirmed earlier findings and agreed with the approach recommended by the oncologists at the Tom Baker Cancer Centre. In the interim, Jennifer’s brother, a physician, suggested genetic testing for certain DNA mutations which could be targeted by treatment. Some lung cancer tumour cells have a mutation that affects the epidermal growth factor receptors (EGFR.) But Jennifer’s tumour did not have the mutation.

In the spring of 2010, Jennifer went through intensive chemotherapy followed by full chest radiation in the fall. The treatment took its toll. She lost all her hair, was frequently fatigued and generally felt unwell a lot of the time.

Fortunately, nausea was less of a problem due to the very effective anti-nausea medicines now available.

When severe headaches showed up in December, tests showed Jennifer’s lung cancer had metastasized to her brain. Full brain radiation followed. The diagnosis of brain metastasis placed her at another “What to Do” point in her life. Jennifer started to research options and found out about stereotactic radiation. She eventually got the treatment with the help of CAREpath, cancer consultants in Toronto, part of her husband’s third party health insurance, which had assisted her throughout in navigating the health system.

CAREpath circulated Jennifer’s brain scans to Canadian centres conducting stereotactic radiation to determine her eligibility for treatment. The response came back as “no,” not advisable. But Jennifer did not give up. She consulted her medical oncologist at Tom Baker Cancer Centre. They recommended she wait a month to allow the full brain radiation treatment to show its full effect.

A month later, CAREpath again circulated her scans but this time a physician in Hamilton, Ontario, agreed to see her. Ten days later, Jennifer underwent stereotactic radiation. Jennifer said the consultants at CAREpath and Lynn Hryniuk especially have been invaluable to her in helping to understand and organize all the various “strings” of information that confront a cancer patient.

Almost two months has elapsed since the stereotactic radiation treatment. Jennifer continues maintenance chemotherapy. She continues to see Dr. Gwyn Bebb, Medical Oncologist and is grateful for the support and care of Dr. Bebb and the medical team at the Tom Baker Centre in Calgary.

Asked where she finds the tremendous will and determination to persevere, Jennifer said that whenever she gets discouraged all she has to do is look at the faces of her two sons.

FREQUENTLY ASKED QUESTIONS ABOUT EGFR (Epidermal Growth Factor Receptors) MUTATION TESTING

What is EGFR? Some lung cancer tumour cells have a DNA mutation that affects the Epidermal Growth Factor Receptors. This is known as having a tumour that is “Epidermal Growth Factor Receptor (EGFR) mutation-positive”. These receptors are found on the cells of the tumour, and they are responsible for telling the tumour when to grow. Mutated EGFRs show an increased rate of uncontrolled tumour growth, which can speed up the cancer’s progression.

Why is knowing your mutation status so important? It is important to know your EGFR mutation status because it can help your doctor determine which treatment will work best for you. In advanced NSCLC (non-small cell lung cancer), there are two main treatment options: chemotherapy and targeted therapy. Tumour cells with mutated

EGFRs (mutation-positive) are constantly signalling the tumour to grow and are therefore, very sensitive to cancer treatments known as “targeted therapies” or “Epidermal Growth Factor Receptor Tyrosine Kinase Inhibitors (EGFR-TKIs)”. Patients who have mutation-negative tumours are usually treated with chemotherapy.

How do I determine my tumour mutation status? To determine if your tumour is EGFR mutation-positive, your doctor has to request a diagnostic test. The test is usually performed on a tumour tissue sample that has been preserved from a previous biopsy.

How much will the EGFR mutation-status test cost? If you qualify for the EGFR mutation-status test, there may be programs in place that will cover the cost for you. Your doctor will know how to obtain coverage.

I have several doctors, which one should I ask to request the EGFR test? Your oncologist is the doctor you should speak to about any questions that relate to your mutation status. That doctor may request EGFR mutation-status tests for patients who meet the criteria.

My doctor says I don’t need to be tested. What should I do now? The EGFR mutation-status test is not for everyone. To start with, you must have advanced non-small cell lung cancer (NSCLC) to be eligible for the test. Having at least one of the factors may increase your chances of having an EGFR mutation. These factors include patients who are non-smokers or ex-light smokers, female, Asian, or who have been diagnosed with adenocarcinoma. Your oncologist will decide whether or not you should be tested.



Streak for Cancer – Making a Difference



Tricia Gray lives in Guelph with her family. In late 2009 she required emergency hospitalization and ultimately was diagnosed with Non-Hodgkin's Lymphoma. She and her husband started a campaign to raise money for collaborative research in support of various types of cancers, including Lung Cancer. To date \$1161.00 has been

donated to Lung Cancer Canada through Streak for Cancer from donors across the country.

To contact, donate or follow see:

streakforcancer@gmail.com

 www.facebook.com.streakforcancer

 www.streakforcancer.blogspot.com

 <http://twitter.com/#!/streakforcancer>

An Update from the 14TH World Conference on Lung Cancer

This year's World Conference on Lung Cancer attracted more than 7000 lung cancer experts from around the world, including representatives from Lung Cancer Canada. **Highlights:**

Reduced Lung-Cancer Mortality with Low-Dose Computed Tomographic Screening

The aggressive and heterogeneous nature of lung cancer has thwarted efforts to reduce mortality from this cancer through the use of screening. Visit: <http://www.nejm.org/doi/full/10.1056/NEJMoa1102873?query=TOC&&>

ALK rearrangement found in nearly 10% of patients in Lung Cancer Mutation Consortium

Lung cancer patients with ALK rearrangement have been found in previous studies to respond well to crizotinib, an ALK inhibitor. Visit: http://www.lungcancer.ca/newsletters/ALK_molecularpdf.pdf

Lung tumor genomes more unstable in nonsmokers vs smokers

Lung tumors in never-smokers showed higher frequencies of copy number alterations and greater proportions of altered genomes compared with those of smokers. Visit: <http://www.oncologyadvisor.com/lung-tumor-genomes-more-unstable-in-nonsmokers-vs-smokers/article/207083/>



The Global Lung Cancer Coalition is set to launch their NEW WEBSITE in time for National Lung Cancer Awareness Month

Highlights and Project Initiatives from the meeting include:

- The GLCC is now distributing Lung Cancer Awareness Leaflets in 13 languages. Visit www.lungcancercoalition.org
- **GLOBAL LUNG CANCER ATTITUDES SURVEY**
All reports available on the website:
<http://www.lungcancer.ca/page1561335.aspx>
- **CLINICAL TRIALS FACT SHEET**
The GLCC has provided created a clinical trials factsheet.
<http://lungcancer.ca/resources/site1/general/PDF/ClinicalTrialsFactsheet-June2011.pdf>
Watch for updated information on Clinical Trials in Canada. Lung Cancer Canada will be listing trials and information this fall.
- **THE GLOBAL LUNG CANCER JOURNALIST AWARD**
In total nine organizations took part, Lung Cancer Canada and The Canadian Lung Association worked collectively to present this award to Alexandra Scott. Visit: <http://lungcancer.ca/lung-cancer-journalism-award-calgary-student.aspx>
- **Global results received to date are available at:**
<http://www.lungcancercoalition.org/journalism/lungcancerjournalism/index.html>. The Global Award will be made in November 2011.

Lung Cancer Canada Attends the 11th Annual Lung Cancer Coalition Meeting

This year's annual Global Lung Cancer Coalition meeting coincided with the World Lung Cancer Conference. The coalition was established in 2001 to serve as an international voice for lung cancer patients. There is representation from 18 countries around the world all of which are committed to improving disease outcomes for all and efforts are focused in the following four key areas:

- Placing lung cancer at the forefront of the global health agenda.
- Lessening the stigma of lung cancer among patients and their caregivers, health care providers, policy makers and the general public.
- Empowering lung cancer patients and their loved ones to take a more active role in their care.
- Effecting change in relevant legislative and regulatory policies to optimize treatment and care of lung cancer patients.

Canadians with lung cancer face challenges in access to new molecular testing and treatment

Lung Cancer Canada advocates that routine molecular testing should be standard for all Canadians diagnosed with this life-threatening disease.

Similar to molecular testing in breast cancer, molecular testing is standard in advanced non-small cell lung cancer, and important for selecting the best treatment.

The epidermal growth factor receptor (EGFR) is an important protein for lung cancer development and growth. Mutations have been identified in the EGFR gene, and are commonly seen in never-smokers with lung cancer. Lung cancer patients with EGFR mutations have dramatic responses to treatment targeting EGFR, called EGFR tyrosine kinase inhibitors (TKI), and have better outcomes than with traditional chemotherapy as initial treatment for advanced lung cancer. Six studies of nearly 1000 lung cancer patients with EGFR mutations have clearly shown that EGFR TKI treatment up front yields greater cancer shrinkage, longer time to cancer growth and better quality of life with fewer side effects than traditional chemotherapy for advanced lung cancer.

Testing and molecularly targeted treatment has been a standard for advanced lung cancer patients worldwide since 2009. Health Canada has approved molecularly targeted treatment for advanced non-small cell lung cancer in 2010, with a drug called gefitinib (Iressa™, Astra Zeneca). However, to date, only British Columbia has approved both routine testing and funding of EGFR TKI treatment as initial treatment for lung cancer patients with EGFR mutations.

Testing and treatments that clearly improve quality of life and cancer outcomes should be available for all Canadians.

Patient Resources



A Patient's Guide to Lung Cancer is a Lung Cancer Canada publication designed to meet the educational needs of lung cancer patients and their families. English and French second edition now available.

Managing Shortness of Breath

Produced by Lorraine Martelli-Reid MN, RN(EC), nurse practitioner Lung DST, Juravinski Cancer Program



The CD consists of a 5 Part Series:

1. Introduction/Learning Abdominal Breathing
2. Managing an acute episode of shortness of breath
3. Sitting to Standing
4. Climbing Stairs
5. Respiratory Muscle Exercises



Lung Cancer Canada Info Sheets are available in English and French.

- Questions to Ask Your Oncologist When You've Been Diagnosed With Lung Cancer
- Lung Cancer and the Use of Oxygen Therapy
- How to Prepare for Lung Cancer Surgery When You Smoke
- Nutrition and Lung Cancer
- For Patients and Caregivers: Coping and Emotional Support
- Thoracic Surgery for Symptom Control
- Managing Daily Activities: Energy Conservation and Work Efficiency

Call or email Lung Cancer Canada to order material.

Material and resources are free for individual patients and caregivers.

ASBESTOS – Our Position

A number of articles have appeared in the media concerning the mining and exportation of Chrysotile Asbestos. These articles take the position that the handling of it should be undertaken under certain strict conditions.

International efforts were recently undertaken to ban the substance by listing it as a hazardous chemical under the Rotterdam Convention. The Canadian Government blocked this effort with the result that the mining and exportation of this hazardous substance continues. Asbestos remains the leading killer of workers in Quebec accounting for 277 of the 493 deaths in the past three years. Handling of asbestos under unsupervised conditions can result in Asbestosis or Mesothelioma both of which can be deadly.

It may be true that handling of this substance under supervised and regulated conditions could make it safe. However to the best of our knowledge Canada does not supervise the handling in those countries importing it.

Canada has strict regulations and controls for handling dangerous substances however there is no assurance any controls are in place in those importing countries.

A CBC investigation indicated how asbestos is being handled in certain countries which clearly showed there are in fact limited or no controls.

Lung Cancer Canada takes the position that Canada should immediately ban the exportation of Chrysotile Asbestos in order to decrease the incidence and morbidity of thoracic malignancies around the world.



Lung Cancer Grove Marks It's 5th Year

Lung Cancer Canada, in partnership with the *Toronto Parks and Trees Foundation* and *Toronto Parks, Forestry and Recreation* initiated this project as both a memorial to those who have died from lung cancer, and a place of healing for survivors of the disease, and for family and friends who have lost a loved one. It is also a place of hope - that lung cancer will be vanquished permanently, symbolized by trees growing and providing ever increasing shelter and comfort.

The design, composed of a network of circular plantings and linear pathways (also lined with trees), is based upon the Aboriginal Medicine (or healing) wheel. In keeping with this theme, the central design point is a large circle circumscribed by eight large natural limestone benches.

"Trees represent the lungs of

the earth, and they are also emblematic of growth and renewal," comments Hailee Morrison, Executive Director, Lung Cancer Canada. "We are pleased that they will stand as a permanent homage to those whose lives have been affected by lung cancer."

Lung Cancer Canada is the only charity devoted solely to supporting those affected by lung cancer through awareness, education and peer support. Call our toll free telephone service at 1-888-445-4403.

Lung Cancer Canada Grove can be accessed through the Sunnybrook Park entrance just north of Eglinton Ave. on the west side of Leslie Street. Follow directional signs for about 300 meters south to the parking lot. The pathway through Seton Park leading to the Grove begins at the east end of the parking lot.



Lung Cancer Grove

Students Helping to Raise Awareness

Students at different elementary schools in the Toronto area have raised awareness of the impacts of lung cancer. In some cases they have created class projects about a family member suffering from lung cancer or

stories in memory of a person who has died of this disease. The projects have included posters with photographs of family members as well as fact and symptom information about lung cancer.

Lung Cancer Canada wishes to acknowledge the following corporate donors:



Lung Cancer Canada is a charitable organization that relies on donations to operate its programs and services. Lung Cancer Canada does not receive any government funding or financial support from any other charitable institution. All donations are greatly appreciated, and tax receipts are issued for amounts of \$25 or more.