

# FIRST-EVER SURVEY SHOWS LUNG CANCER PATIENTS AND CAREGIVERS FACE AN OVERPOWERING AVALANCHE OF INEQUITIES

Lung Cancer Canada Launches the Second Annual Report on Canada's #1 Killer

#### **Report Highlights**

In an online survey of 91 Canadians with lung cancer and 72 caregivers, Lung Cancer Canada discovered that here in Canada:

- 61% of caregivers reported feeling anxious or stressed compared to 42% of patients.
- More than half of caregivers (59%) reduce the number of hours they work, and a further 8% quit their jobs to look after a loved one with lung cancer.
- 50% of caregivers reported a negative impact on their household financial situation.
- Only 26% of caregivers reported receiving social support services and/or counseling.
- Lung cancer diagnosis and treatment is unequal based on where Canadians live access to diagnostic tools and treatment vary province-to-province and even among postal codes.
- Survivorship in lung cancer is handicapped by late diagnosis.'
- Smoking is on the decline the majority of Canadians diagnosed with lung cancer today are ex-smokers, and many victims never smoked at all.

TORONTO, ON, November 3, 2015 – Lung Cancer Canada has released its second annual report, *The Faces of Lung Cancer: One Patient, One Diagnosis, Countless Casualties*, an in-depth look at lung cancer today in Canada that places a focus on both patients and their circles-of-care. Providing new perspectives on the country's deadliest cancer, the report indicates a virtual avalanche that devastates and impacts countless lives and systems in its path. In a disease with low survival rates around the world, Canada is at risk of failing patients and caregivers with obstacles to accessing life-prolonging treatment, limited research investment and inadequate availability of local support services, as well as a concerning lack of compassion for those patients and caregivers struggling with the disease, every day.

"There are still so many misconceptions about this disease – people with lung cancer and their families are in a fight for their lives, but they must overcome many obstacles in addition to fighting their illness," says Dr. Natasha Leighl, medical oncologist and Lung Cancer Canada President. " As the most commonly diagnosed cancer today in Canada, screening and early detection will not only save lives, but may have a positive impact on how we spend our health care dollars. Just imagine the power to cure lung cancer instead of finding it too late, and at a lower cost per case. Despite these facts, not one province has adopted a comprehensive screening program for lung cancer."

The patient and caregiver survey explored patient and caregiver experiences with lung cancer, treatment and supportive therapies, challenges associated with symptoms, treatments, treatment decision making, and unmet needs. The results speak to an incomplete circle of care in lung cancer, one that presents a significant impact on both patients and caregivers throughout their cancer journey. Caregivers, in particular, appear to feel the weight of lung cancer more acutely than the patients themselves, identifying the hidden emotional burden of this disease.

Quality of life was a dominant theme in the survey and respondents cited that fatigue and a lack of energy by patients (64%) and caregivers (65%), as the most challenging symptoms of lung cancer to manage. Unsurprisingly, eight out of ten caregivers emphasized the stress associated with their caregiving experience. The most common sources of stress for caregivers are dealing with the care receiver's declining health (66%) and managing their own emotions (63%).

The deep-seated perception that lung cancer is self-inflicted places an additional burden on families. This negative stigma prevails despite the fact that the majority of Canadian lung cancer patients are ex-smokers, and many never smoked at all. Of particular interest, caregivers indicated that they experienced the lung cancer stigma more than the patients themselves (26% versus 18%). Thirty-eight per cent of caregivers felt more emotionally burdened than the patients.

"When people asked if my dad smoked, I realized they likely weren't sympathetic," says Christina Amaral, from Toronto whose dad Ed passed from lung cancer. "It is a stigma that follows lung cancer, even for those who didn't smoke. It's frustrating for all of us. If my dad had been diagnosed with another cancer people would have been more inclined to learn about his illness and provide support rather than immediately show disinterest. Once I tell people that my dad died from lung cancer I know that they have already formed a negative opinion about his lifestyle choices".

When asked what would make caregiving easier to manage, the top two answers point to stigma and support: caregivers most often mention greater empathy towards lung cancer in general and better access to support services. Better financial resources and help with caregiving tasks also ranked highly. However the survey showed that only 26% of caregivers had ever received such healthcare support services. Even when these services are offered, wait times and access points can differ between provinces, regions, and cities.

Christina's mom Maria adds, "I tried to be strong and positive for Ed and for my family. I had this facade of normalcy when inside it was overwhelming and frustrating. I was angry that my young and vibrant husband was being taken from us. It was hard enough balancing the cancer with working full time, being a mom, and being a supportive wife without the additional indignity of Ed being judged because he had lung cancer. They automatically assumed he was a smoker."

According to Dr. Paul Wheatley-Price, medical oncologist and Chair of Lung Cancer Canada's Medical Advisory Committee, managing a cancer diagnosis takes an entire team and support plays a key role in achieving successful outcomes for patients, "Canada is not yet making it easy for lung cancer patients and their caregivers, whether it is accessing treatment or getting the right support. And your postal code still matters, depending on where a patient lives, it can impact how quickly they are diagnosed, the support they can access, and how long it will take to see a specialist and receive treatment."

Lung cancer is the most common cancer, and by far the leading killer of all cancers in Canada. ii

- Every day, 57 Canadians will die from lung cancer.
- Every hour, 2 Canadians will lose a loved one to lung cancer.
- Lung cancer accounts for 25 per cent of all cancer deaths in Canada.
- The five-year survival rate for lung cancer is only 17%.

Although lung cancer has the highest mortality of all cancers in Canada, iii there is a disproportionate amount of research investment allocated to it compared with both the scope of the cancer and with other cancers. In fact, as of 2012, significantly more funds were going into research for breast cancer and prostate cancer. While it is important that these cancers continue to receive research funding, it is also important to acknowledge the obvious need for more investment in lung cancer research that, at the very least, matches the significant burden of this disease. Indeed lung cancer kills more Canadians a year than breast cancer, prostate cancer and colorectal cancers combined.

Cancer patients and their caregivers continue to face a number of significant challenges, as outlined in the report. Irrespective of whether someone smoked or not, Lung Cancer Canada believes that Canada, as an inclusive and tolerant society, should be advocating for all patients with lung cancer, who all are deserving of the best care available. Lung Cancer Canada urges all Canadians to step-up and advocate for everyone who suffers from lung cancer.

For more information on lung cancer and to view a copy of the *Faces of Lung Cancer* report, please visit: www.lungcancercanada.ca.

## **About Lung Cancer Canada**

Based in Toronto, Lung Cancer Canada (LCC) is Canada's only national charitable organization that is solely focused on lung cancer. Lung Cancer Canada serves as Canada's leading resource for lung cancer education, patient support, research, and advocacy. LCC's mission is four-fold: 1) to increase public awareness of lung cancer, 2) to support and advocate for lung cancer patients and their families, 3) to provide educational resources to patients, family members, healthcare professionals, and the general public, and 4) to raise funds in support of promising research opportunities.

### For more information and to arrange for interviews, please contact:

Ethan Pigott 416-558-2783 ethan@pigott.ca

Christina Sit <a href="mailto:christinasit@lungcancercanada.ca">christinasit@lungcancercanada.ca</a> 416-937-8899 416-785-3439

#### REFERENCES

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ii Canadian Cancer Society. National Cancer Institute of Canada: Canadian Cancer Statistics 2015. iii Canadian Cancer Society. National Cancer Institute of Canada: Canadian Cancer Statistics 2015.