Start Asking the Right Questions About Lung Cancer

A Roadmap for Lasting Change

Second Edition

lung health foundation | LUNG CANCER CANADA

WHAT'S INSIDE

A lot has happened in the year since the first edition of this report was published.

We lost an estimated over 21,000 Canadians to lung cancer.[1] That number continues to grow by 58 people every single day.

Over 29,000 more Canadians were diagnosed with lung cancer in the last year too. There would have been more had the COVID-19 pandemic not continued to grip the world. It compelled a lot of people who have symptoms to avoid getting checked. And, it brought the diagnosis processes to a near halt with infection-prevention control measures that limited waiting room capacity and reallocated time spent on patients to time spent disinfecting surfaces between tests.

The news wasn't all bad.

A pilot lung cancer screening program in Ontario was made permanent. Now, people at higher risk who may feel fine can be screened to detect lung cancer before it's too big to treat or spreads to other parts of the body. While there is limited capacity with four sites in the province and work needed to gain awareness of the program, no doubt this program will save lives.

What hasn't changed is the stigma associated with lung cancer because it's still seen as a "smoker's disease." It's not and the judgement implies some people deserve to get sick. That's wrong and unfair. Without exception, everyone facing cancer deserves the same compassion and care.

This second-edition report is once again a joint effort between the Lung Health Foundation and Lung Cancer Canada. Together, we continue to expose the impact of stigma, urging Canadians to stop asking the wrong question – did you smoke? – and start asking the right questions like why lung cancer is by far the largest cancer killer but is the least funded or why survival rates have barely improved in decades. We also again present the urgent challenges in the healthcare system with solutions to help.

Please join our mission to end the blame and shame to give people battling lung cancer the same fighting chance as anyone else facing a cancer diagnosis.

Don’t ask Phil whether his late wife smoked.

The answer doesn’t make him miss her any less.

THE WRONG QUESTION: DID YOU SMOKE?

When someone gets lung cancer, they are quickly confronted with “did you smoke?”

Friends, family, healthcare providers and others ask the question as if to determine whether the person facing a life-threatening diagnosis “deserved” it. The answer is too often used as a qualifier for how much care and compassion is given.

“Did you smoke?” is rooted in a long-standing stigma based on the myth that lung cancer is a smoker’s disease. It’s not. If you have lungs, you can get lung cancer.

While it’s accurate that smoking, particularly cigarettes, is the leading cause of lung cancer, that’s only a part of the story. Other things can cause lung cancer too, including exposure to asbestos, radon and certain occupational chemicals. Also, family history and outdoor air pollution are known factors as well.

Regardless, **people with lung cancer face blame and shame – whether they smoked or not.**

And even if they did smoke, it doesn’t matter. Whatever a person’s risk factors were before their diagnosis, they deserve care and compassion after diagnosis.

“Did you smoke?” is the wrong question. The answer doesn’t matter. It perpetuates an unfair stigma that persists, in part, because smoking is seen as a bad habit rather than the serious addiction it is.

The sooner we can drop the judgment to end stigma, the sooner people with lung cancer can get the full support and help they need for the fight of their lives.

Don’t ask WIng-Si if her mom smoked.

The answer doesn’t mean she misses her any less.

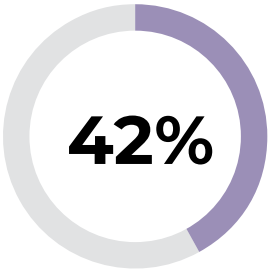
THE IMPACT OF STIGMA

The myth that lung cancer is a smoker's disease has deadly consequences.

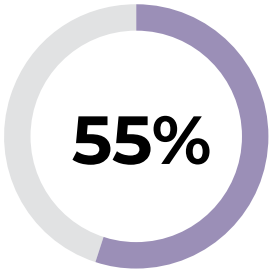
Non-smokers may ignore symptoms under the false belief it couldn't possibly be lung cancer because they never smoked. Their healthcare providers may dismiss lung cancer as a possible cause of symptoms too. As a result, valuable treatment time may be lost to delayed diagnosis and more people could die from the disease.

On the flip side, many who do smoke or used to smoke hold off on going to the doctor for symptoms fearing the judgment that "they did it to themselves." Symptoms get worse, cancer can spread and the outcome gets bleaker than it would have been had they felt comfortable going when they first suspected something could be wrong.

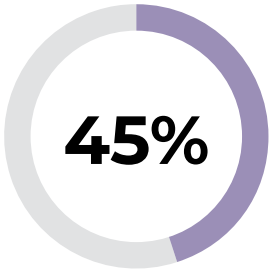
The blame and shame that comes with lung cancer adds an emotional burden to an already overwhelming situation. Many experience guilt and shame – whether they smoked or not. And it gets worse:



feel less deserving of help



experience social isolation



put off doctor visits due to self-blame

[2]

Lung cancer stigma leads to hiding a diagnosis as well. Even families hesitate to talk about the lung cancer of a loved one. The fear of judgment robs patients, caregivers and families of support when they need it the most.

A recent study on cancer funding disparities noted the blame culture of lung cancer has led to under-funding potentially life-saving research.[3] It's particularly worrisome that lung cancer is by far the largest cancer killer in Canada, yet it's the least funded, in part due to stigma.

We need to change the conversation about lung cancer from blame and shame to one that offers care and compassion so we can save lives.

Don't ask Joey
if he smoked.

The answer doesn't make it any easier to sing with most of his right lung removed.

HOW TO STOP THE STIGMA OF LUNG CANCER

Public education is the key to eliminating the unfair barrier and burden lung cancer stigma creates for people with lung cancer.

Campaigns proven effective at changing perceptions, such as the joint Lung Health Foundation and Lung Cancer Canada *Stop Asking the Wrong Question* campaign, need to be widespread and ongoing. Government funding is needed to support these efforts, as well as education for Canadians about risk factors and symptoms.

Education for healthcare providers is needed too. It should address the unconscious bias associated with lung cancer and how it affects care. Providers should also be educated on how to support patients dealing with stigma.

To further support provider education, professional bodies, such as the College of Physicians and Surgeons, should routinely measure the attitudes of providers on lung cancer and lung cancer treatment.

Education is also needed to improve tobacco cessation treatment with a focus on overcoming addiction.

Individually, we need to stop asking the wrong question – did you smoke? – and start asking the right questions that look for meaningful ways we can support people with lung cancer to ensure they receive the care and compassion they need and deserve.

Don’t ask Heather
if she smoked.

The answer shouldn’t decide whether you’re rooting for her.

RECOMMENDATIONS TO HELP PEOPLE LIVING WITH LUNG CANCER

Inside the healthcare system, there are long-overdue changes needed to save the over 80% of Canadians with lung cancer will die within five years of diagnosis. We need to:

- increase access to screening programs to find lung cancer sooner while curative treatment is still possible **page 12**
- increase how fast people are diagnosed to ensure valuable time is not lost waiting in the system **page 14**
- increase access to molecular testing to give people with lung cancer the most effective treatment possible **page 15**
- quicken approval of funding for medication proven safe and effective
- lower the cost of lung cancer medication so all Canadians have access, regardless of age or income **page 17**
- improve access to mental health services and social support for people with lung cancer, their families and caregivers **page 19**

We need to increase access to screening programs to find lung cancer sooner while a cure is still possible.

BACKGROUND

In lung cancer, early detection is everything.

When someone is diagnosed in an early stage before symptoms start, the chances for survival are very good. When someone is diagnosed in a later stage, the chances for survival go down dramatically because there are fewer options for treatment.

For example, the five-year survival rate for late-stage, non-small cell lung cancer is 10 to 36 per cent.[4] However, when caught in an early stage, the survival rate boosts to 47 to 92 per cent.

Early detection is made possible through screening programs.

With the proper screening programs in place, lung cancer is diagnosed at an early stage about 75 per cent of the time.

These programs are not expensive, save lives and save much-needed healthcare dollars that would otherwise be spent treating late-stage cancer.

WHAT'S BROKEN

About 70 per cent of lung cancer is diagnosed at a late stage, when it's resistant to treatment and incurable – in part **because Canadians don't have widespread access to screening programs.**[5]

Lung cancer is the only cancer recommended for organized screening by the Canadian Task Force for Preventative Health that still has insufficient programs. Sadly, only two provinces have committed to screening programs for lung cancer: Ontario (as of 2021) and British Columbia (as of 2022). That's a stark difference compared to widespread screening programs for other cancers like breast, colorectal, or cervical cancer.

There are already big differences in survival rates between provinces and the lack of screening programs make it worse. For example, the five-year survival rate for lung cancer is the highest in Manitoba, Ontario and New Brunswick at 20 to 21 per cent. Elsewhere the rate dips to 16 to 18 per cent.[6]

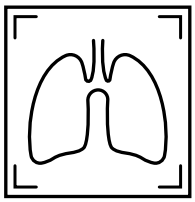
In the places that do have screening programs in some form, not enough people know about them. Public education campaigns are needed to increase awareness and encourage participation.

HOW WE CAN FIX IT

All provinces and territories should **expand current cancer screening programs to include lung cancer for those at higher risk.** Annual screening for up to three years is recommended.

Also, a joint task force with Ministry of Health representatives from all provinces and territories should be developed at a health ministers' meeting with the goal to create best practices and guidelines for universal use across Canada.

For new and existing screening programs, funding should be set aside for public education campaigns to ensure those at higher risk are aware they should be screened and where to get screened to increase participation. Pan-Canadian Early Detection of Lung Cancer study, published in 2014 found:



The average cost of lung cancer screening in Canada is only

$453

per person.

The average cost for surgery to cure lung cancer at an early stage is

$33,344

per person.

Screening and surgery costs combined are less than the average cost of

$47,792

per person needed to treat late stage lung cancer with chemotherapy, radiotherapy or supportive care.[7]

We need to increase how fast people are diagnosed to ensure valuable time is not lost waiting in the system.

BACKGROUND

Rapid-diagnosis assessment programs, also known as diagnostic assessment programs, are the most efficient and effective way to diagnose lung cancer. These programs bring together a multidisciplinary team of health professionals to streamline diagnosis, inform patients and provide support.

Nearly 60 per cent of lung cancer patients in Ontario, who can access these programs, are diagnosed within 28 days. In a cancer that can kill quickly, every day matters.

At their best, these programs include a "navigator," someone assigned to help people with lung cancer through the complex and often confusing health system. Including navigators in the process increases how often patients get molecular testing, reduces wait times for treatment and helps maximize time with doctors.

WHAT'S BROKEN

Not all Canadians have access to rapid-diagnosis assessment programs or diagnostic assessment programs. As a result, the time between suspecting lung cancer to diagnosis and treatment is different across the country, **leaving some waiting and worrying longer than they should have to.**

In British Columbia and Quebec, there is unequal access even within the same province due to a limited number of these programs. **Those living in Saskatchewan, Nova Scotia and Nunavut are shut out entirely.**[8]

HOW WE CAN FIX IT

Healthcare systems in all provinces and territories should have ***w*idely-available rapid-diagnosis assessment programs or diagnostic assessment programs for lung cancer that include a patient navigator.** Rather than endure an agonizing wait of months filled with tests and multiple doctor referrals to multiple specialists, that time will be better spent undergoing potentially life-saving treatment.

We need to increase access to molecular testing to give people with lung cancer the most effective treatment possible.

BACKGROUND

One of the biggest breakthroughs in lung cancer treatment is the discovery that it's not a single disease but actually dozens of diseases – each with their own molecular variation. Identifying those variations can open up new cancer-fighting possibilities in the form of targeted therapies.

Targeted therapies fight cancer cells through attacks on specific targets on or inside of them. Traditional "one-size-fits-all" treatments like chemotherapy, on the other hand, tend to attack healthy cells too. For a person with lung cancer, targeted therapies can mean fewer side effects and a better quality of life.

The first step toward targeted therapies is molecular testing of a tissue sample from the tumor, also known as biomarker testing.

WHAT'S BROKEN

Canadians struggle to get molecular testing because of challenges approving, reimbursing and accessing tests.

Also, regulatory and administrative processes to support access to molecular testing are not standardized across the country and not keeping pace with innovation in cancer treatment. As a result, **some Canadians have access while others are left trying to survive without targeted therapies they may be eligible for.**

HOW WE CAN FIX IT

The federal government should develop a national molecular testing framework to guide provinces and territories on how to improve access to testing for Canadians with lung cancer.

We need faster approval of funding for medication and treatment proven safe and effective.

BACKGROUND

In Canada, the federal government works with provincial and territorial governments to determine which medications are safe and should be funded. Here's how they work together:

- The federal government approves which drugs are safe for Canadians through Health Canada.
- The Canadian Agency for Drugs and Technology Assessment conducts a health technology assessment that examines the value of a drug in the current healthcare system. Most provinces and territories rely on this assessment to decide what they will fund. Quebec conducts its own assessment through Institut national d'excellence en santé et services sociaux
- The pan-Canadian Pharmaceutical Alliance facilitates national price negotiations.
- Provincial and territorial governments decide which approved drugs they will pay for within their health systems so patients can get them at low-cost or no-cost.

These steps give Canadians access to medication and treatment proven safe and effective.

WHAT'S BROKEN

The time between when a drug is approved federally to when provinces and territories approve public funding is two-to-five years.[9] That's too long. **People are quite literally dying waiting for medication that could help them.**

Because each province and territory independently approves which drugs they will pay for, potentially life-saving treatment is not always available equally across the country. While there has been progress to limit duplicating processes between provinces and territories, more needs to be done.

Also currently, there are no guidelines for how long it should take to negotiate prices with manufacturers.

HOW WE CAN FIX IT

The pan-Canadian Pharmaceutical Alliance should develop a system to shorten the wait times that is aligned with related review processes by the Canadian Agency for Drugs and Technologies in Health.

We need to lower the cost of lung cancer medication so everyone has access, regardless of income.

BACKGROUND

Oral cancer drugs are medication taken by mouth in the form of a tablet, capsule or liquid. Patients can take this medication at home as part of their treatment rather than at a hospital.

For example, oral chemotherapy can be prescribed instead of chemotherapy given by infusion.

WHAT'S BROKEN

Oral cancer medication is not equally funded in Canada.[10] Residents of some provinces and territories get it for free, while those living elsewhere have to pay out of pocket. Ontario and the Atlantic provinces, in particular, fall behind the rest of the country. For example, Tagrisso (osimertinib) costs nearly $300 per day, adding up to $8,000 for an average 28-day treatment.

A person's age can lead to high costs too. For example, in Ontario, oral cancer medication is only covered under the Ontario Drug Benefit and the Trillium Drug Program for those aged 65 or older, receiving social assistance or with limited private insurance. However, cancer drugs given in hospitals are publicly covered for all Ontarians regardless of age.

The high cost and unequal access of lung cancer medication mean some Canadians have a better fighting chance because of where they live or how much money they make. It's unacceptable.

HOW WE CAN FIX IT

All provinces and territories should develop and expand their home cancer drug programs so all Canadians can equally access oral cancer drugs, regardless of age or income.

We need to ensure Canadians living in all areas of the country have equitable access to lung cancer care.

BACKGROUND

Like all cancers, treating lung cancer requires a specialized team of healthcare providers and medical equipment to provide a range of treatment options. In many of Canada's larger cities, there are centers dedicated to caring for the unique needs of people with cancer that also offer specialized services.

WHAT'S BROKEN

Canadians have unequal access to treatment options because of where they live.

Often, those in Canada's larger cities have more access than those in remote areas. For example, stereotactic body radiation therapy (treatment with extremely precise, very intense doses of radiation) is not available in Newfoundland and Labrador or in the territories.

Those unable to access treatment where they live must temporarily move or regularly travel as far as six-to-10 hours away, forcing the patient and their caregivers to take substantial time off work while racking up significant travel costs.

Canadians who live in areas with the least access tend to have lower incomes, making the burden even harder to bear. For some, it's just too much so they don't get treatment at all.

HOW WE CAN FIX IT

All Canadians should be treated as close to home as possible with the same standard of care. To do so, health systems need to identify and increase resources for community hospitals and regional centres that can support excellent cancer care.

For example, adding more chemotherapy infusion sites in smaller communities will allow more Canadians living in remote areas to receive treatment closer to home and decrease how long they have to wait to access care.

We need to improve access to mental health services and social support for people with lung cancer, their families and caregivers.

BACKGROUND

Lung cancer is a lot to deal with. Patients, their families and caregivers can experience fear, stress, anxiety and depression. New symptoms, spreading cancer and side effects from treatment can make it all even harder to endure.

Feelings and concerns can change with a person's age or the stage of cancer. For example, those diagnosed in their younger years face the disease while raising families and building careers during what is often their best income-earning years. For seniors, there can be medical issues associated with aging happening at the same time. Palliative patients may grapple with end-of-life care and symptom management.

Receiving mental health care and social support can minimize stress, improve quality of life, treat depression and/or anxiety and improve coping skills. It can include education and peer support, as well as services from social workers and counsellors, psychologists and psychiatrists.

WHAT'S BROKEN

Not everyone with lung cancer is provided opportunities to receive mental health care and social support in combination with the medical treatment.

Sadly, some avoid reaching out for help entirely fearing they will be judged because of the stigma associated with lung cancer.

HOW WE CAN FIX IT

People diagnosed with lung cancer should be screened for distress with a clinically-validated tool. Those who are in distress should be referred for additional care relevant to their needs.

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lung health starts now

lung health foundation

ABOUT THE LUNG HEALTH FOUNDATION

The Lung Health Foundation is the leading health charity dedicated to improving lung health through a uniquely integrated approach that identifies gaps and fills them through investments in ground-breaking research and urgently needed programs and support, policy and practice change, and promoting awareness about lung health issues affecting all Canadians.

LUNG CANCER CANADA

ABOUT LUNG CANCER CANADA

Lung Cancer Canada is a national charitable organization that serves as Canada's leading resource for lung cancer education, patient support, research and advocacy. Based in Toronto, Ontario, Lung Cancer Canada has a wide reach that includes both regional and pan-Canadian initiatives. Lung Cancer Canada is a member of the Global Lung Cancer Coalition and is the only organization in Canada focused exclusively on lung cancer.