

Start asking the right questions about lung cancer:

A Roadmap for Lasting Change



lung health
foundation



LUNG
CANCER
CANADA



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 groundbreaking research and urgently needed programs and supports; policy and practice change; and promoting awareness about lung health issues affecting all Canadians.



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.

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Foreword

Start Asking the Right Questions About Lung Cancer: A Roadmap for Lasting Change provides a picture of lung cancer in Canada. A collaboration of the Lung Health Foundation and Lung Cancer Canada, this report addresses the social, economic and mental health issues of Canadians living with lung cancer and aims to provide solutions to these challenges.

This report can help decision makers create an environment that will better support more effective and timely diagnosis and treatment and provide a strong base for education, awareness and advocacy to help reduce the stigma regarding the disease—so that we can start asking the right questions about lung cancer.

Executive Summary

It is estimated that 29,800 Canadians will be diagnosed with lung cancer in 2020.¹ Lung cancer is the leading cause of cancer death in Canada and more people are expected to die from the disease than from colorectal, breast and pancreatic cancer combined.²

Start Asking the Right Questions About Lung Cancer: A Roadmap for Lasting Change aims to contribute to creating a system with improved education and awareness regarding lung cancer and to help ensure patients have access to the diagnostic screening, psychosocial support and effective treatments that will lead to proper diagnosis and treatment of their disease.

This report focuses on three specific challenges:

- Access to diagnostics and care
- Stigma
- The need for psychosocial support

Access to Diagnostics and Care



Early detection of lung cancer improves survival rates and allows for more treatment options. This requires early and sufficient access to screening and increased referrals to multidisciplinary teams and specialist care, which remain clinical best practice and improve patient outcomes. While there have been numerous scientific advancements and innovations in treatments, once diagnosed, many patients are waiting too long for access to the medicine they desperately need. Some will even die waiting due to a drug approval process that is fragmented and inconsistent.

Stigma



A variety of risk factors may contribute to the development of lung cancer, for example, exposure to toxic substances, pollution, smoking and family history. While smoking is prominent among these risk factors, approximately 15 per cent of people with lung cancer have never smoked.³

People living with lung cancer experience stigma, from their communities, health providers and employers and even friends and family. One study showed that about 30 per cent of people with lung cancer blame themselves for their diagnosis.⁴ Because smoking is seen as the main cause of lung cancer, people with lung cancer often feel blamed for their illness. This can affect their ability to receive support and cause them to feel they don't deserve care and compassion.

Psychosocial Support



People living with lung cancer experience high levels of anxiety and depression. It is important that they have access to informational and psychosocial support. This support helps to minimize stress, improve quality of life, treat depression and anxiety and enhance coping skills.

Overview

There are two types of lung cancer:

- Small cell lung cancer (SCLC) grows quickly and often spreads to other parts of the body. This type of cancer is linked to cigarette use and not often seen in those who do not smoke.
- Non-small cell lung cancer (NSCLC) is the more common type of lung cancer (80-85% of cases) and grows more slowly.

In 2020:

- 29,800 Canadians will be diagnosed with lung cancer this year. This represents 13% of all new cancer cases in 2020.
- 15,000 men will be diagnosed with lung cancer and 11,000 will die from it.
- 14,800 women will be diagnosed with lung cancer and 10,200 will die from it.
- 21,200 Canadians will die from lung cancer.
- 58 families lose a loved one to lung cancer every day in Canada. It is responsible for 1 in 4 cancer deaths.

In Canada, the five-year net survival rate for lung cancer is 19%. This means that about 19% of people diagnosed with lung cancer will survive for at least five years after their diagnosis.

It is estimated that about 1 in 14 Canadian men will develop lung cancer during their lifetime and one in 16 will die from it.

It is estimated that about 1 in 15 Canadian women will develop lung cancer during their lifetime and one in 19 will die from it.

Risk Factors

The risk of developing lung cancer increases with age. More than half of all newly diagnosed lung cancer cases occur among people aged 60 years or older. Men develop lung cancer slightly more often than women.

Smoking tobacco, particularly cigarettes, is the main cause of lung cancer. About 72 per cent of lung cancer cases in Canada are due to smoking tobacco. Other risk factors include personal history of lung disease, family history of lung cancer and exposure to second-hand smoke, asbestos, certain occupational chemicals and outdoor air pollution. Exposure to radon is the leading cause of lung cancer in non-smokers and the second leading cause of lung cancer in smokers.

Source for above statistics: Canadian Cancer Society

Burden and Challenges of Lung Cancer in Canada



Access to Quality Diagnostics and Care

Lung Cancer Screening

In lung cancer, early detection is everything. If a high-risk individual is diagnosed before the onset of symptoms, when the cancer is in an early stage, the chances of survival are very good. For example, estimates of five-year relative survival rates for non-small cell lung cancer in the United States range from one per cent to 10 per cent across the sub stages of stage IV and from 68 per cent to 92 per cent for the sub stages of stage I.⁵

But access to screening is not equal across Canada, complicated by the country's vast geography and shortage of universal screening programs. To illustrate this, lung cancer survival rates within stage groups vary from province to province. For example, the two-year relative survival for stage I lung cancer ranges from 66.5 per cent in Prince Edward Island to 84.8 per cent in British Columbia. The two-year relative survival for stage IV also varies, ranging from 7.6 per cent in Manitoba to 13.2 per cent in British Columbia.⁶ While demographics may partly explain these differences, this suggests that differences in detection and access to treatment may be putting patients at a disadvantage and hampering survival rates. Furthermore, Canadians in rural and remote areas have a higher incidence of lung cancer compared to those in urban areas. While this may be due in part to differences in smoking rates, it may also be more difficult for people in rural and remote areas to access screening, diagnosis and treatment.

In Canada, almost 50 per cent of lung cancer is diagnosed at stage IV, an incurable stage. With the proper screening protocols in place, 75 per cent of diagnoses are at an early stage, when curative treatment is possible.⁷

For example, the Canadian Task Force for Preventative Health recommends lung cancer screening using low dose CT (LDCT) “for adults aged 55–74 years with at least a 30 pack-year smoking history who currently smoke or quit less than 15 years ago.” Annual screening up to three consecutive times is recommended.

Rapid-Diagnostic Assessment Programs

Rapid-diagnosis assessment programs (RDP) or diagnostic-assessment programs (DAP) manage and coordinate care from referral to diagnosis. Diagnosis includes staging work-up, development of a treatment plan and next steps for patients with a cancer diagnosis. Once referred into a DAP, patients have access to a multidisciplinary care team, which includes a patient navigator, who is the patient's main contact and supports the patient throughout the diagnostic process.

DAPs streamline the diagnostic process, help inform patients and provide support. Involvement of the navigator helps reduce wait times to treatment, increase frequency and availability of molecular testing results at consultation and improve allocation of time-constrained physician resources. Yet, RDP and DAP facilitated by navigators are not available in all provinces.

In Ontario, 59 per cent of individuals suspected of having lung/thoracic cancer who were assessed through a RPD/DAP were diagnosed within the 28-day target following a referral. This is moving closer to Cancer Care Ontario's target of 65 per cent. Yet, despite proven effectiveness, RPD/DAPs are limited in some provinces, such as British Columbia and Quebec, and these programs are unavailable in other provinces, including Saskatchewan, Nova Scotia and Nunavut.⁸

Treatment Options

Access to lung cancer treatment is complicated by Canada's vast geography and diverse cultures, as well as by how Canada's healthcare system is set up. Healthcare is a partnership between federal and provincial governments. Health Canada, a federal body, approves drugs, but provinces oversee the listing and administration of healthcare. The situation is complex, especially in this era of new surgical techniques and treatments. But while treatments have modernized, our healthcare system has struggled to keep up.

Many lung cancer management options available in big and medium-size cities in British Columbia, Alberta, Saskatchewan, Manitoba, Ontario and Quebec are limited or not available in the remote northern areas of the same provinces or in the Yukon, the Northwest Territories and Nunavut. For example, sites for stereotactic body radiation therapy (SBRT), cancer treatment that delivers extremely precise, very intense doses of radiation to cancer cells in a certain area while minimizing damage to healthy tissue, is not available in Newfoundland and Labrador or the territories.

There is a need for access to specialists, diagnostic techniques and newer treatments in remote sites. Such access would substantially reduce travel to urban sites and reduce the burden on caregivers, since travel can take as long as six to 10 hours and much longer in the winter months. Furthermore, many Canadians in rural areas earn less money than those

in cities, which can have a huge impact on patients and their caregivers. Travel and associated costs play a significant role in patients' acceptance or denial of treatment, increased stress and financial burden.

Patients need to be treated as close to home as possible while maintaining excellence. The roles for community hospitals and regional centres of excellence in all provinces need to be better identified. Services such as additional chemotherapy infusion sites within smaller communities can help patients receive treatment closer to home and decrease wait times.

Medication

Lung cancer care options are rapidly evolving and survival has improved, thanks to improved chemotherapeutic agents and the discovery of second and third generation therapies. But despite numerous scientific advancements and innovations, many patients are waiting too long for access to the precision medicine they desperately need. Some will even die waiting due to a drug approval process that is fragmented and inconsistent.

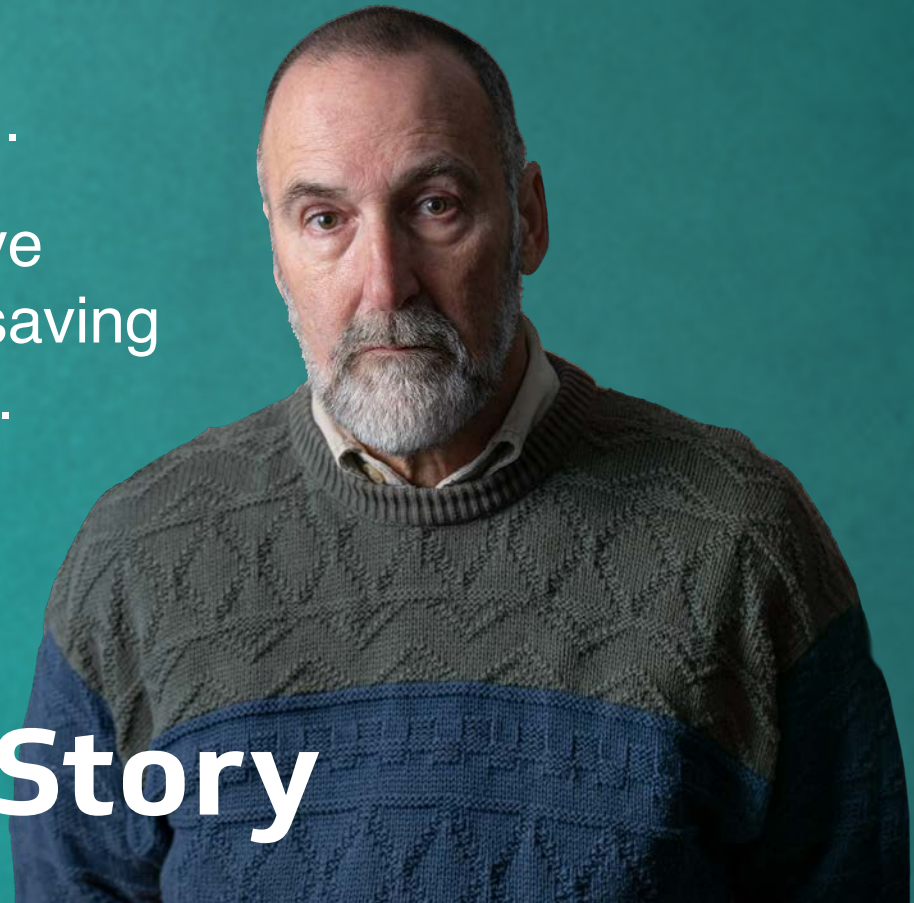
One of the most profound changes to the lung cancer landscape has been the discovery that lung cancer is not a singular disease but dozens of diseases, each with a unique molecular genetic alteration. The scientific community is working to find treatments that target each of these genetic variants. Only a decade ago, the thought of being treated with a medicine designed for your specific genetic makeup or modifying your own immune cells to fight cancer, would have seemed impossible. Today it's becoming a reality.

Despite this progress, many Canadian patients are waiting too long for access to these new therapies due to long drug approval processes and prohibitive prescription costs. An integrated strategy around precision medicine delivery will require a collaboration between many organizations to address the system barriers, funding silos and out-of-date policies that are preventing patients' timely access to treatment.

Don't ask
whether I smoked.

Ask whether I have
access to the lifesaving
treatments I need.

Angus's Story



In early 2018, Angus Pratt felt *something* in his chest. He ignored it.

When he finally saw his doctor, he had a lump in his right breast and one in the left.

History repeated itself. When he was just a teenager, Angus lost his mother to breast cancer. His brother had it too. Now, Angus.

His official diagnosis was intraductal carcinoma of the breasts. Additional tests uncovered a lung tumour – IIIC non-small cell adenocarcinoma.

“The first time I told someone, their first question was, ‘You weren’t a smoker were you?’ At first, I would just say no. But as time goes on, I get more irritated by that question. That’s not really the issue. If you have lungs, you are a candidate for lung cancer,” says Angus, a freelance web developer and first-aid worker.

Treatment was intense. Angus went through six cycles of chemotherapy and 30 days of radiation. Six weeks after that, he had a bilateral mastectomy for his breast cancer. Next up was immunotherapy for the lung cancer. Unfortunately, it had progressed to stage IV in just a few months.



His doctor recommended osimertinib (Tagrisso®) as a first-line therapy because it's highly effective for his type of tumour, has fewer side effects than older-generation EGFR inhibitors, leads to better life expectancy and increased quality of life.

At the time, osimertinib was not publicly funded as a first line treatment despite its recommendation by the pan-Canadian Oncology Drug Review. Without access to a clinical study or private insurance, the medication costs as much as \$9,000 per month.

Some patients are forced to seek crowd-funding for treatment or they're left to make tough choices. It's not an uncommon situation. Many new cancer treatment drugs are approved but not yet funded, resulting in delayed, or no access.

For Angus, he could take afatinib (Geotrif®) instead. It's been effective so far, but has more side effects like weekly diarrhea, a nasty red eczema rash, pimples and slight cognitive lapses.

"It's frustrating for me, and no doubt other patients," he says. "Governments and drug companies need to talk more to each other and work hard to resolve the pricing and funding issues."

Angus has endured a lot in a short time. His wife, Yvette, passed away from pancreatic cancer in 2018, leaving him a widower with three sons. Now, cancer.

Still, he looks for beauty in everyday moments and in the world around him. He loves going for walks and has taken up watercolour painting. He provides first aid on high hazard job sites and does advocacy work for Lung Cancer Canada.

"Cancer is not a death sentence, it is an eye opener," says Angus. "It's a wake-up call and it's a call to live life. But it isn't a death sentence. Life is about living, so get out there and enjoy it."

The first time I told someone, their first question was 'You weren't a smoker were you?' At first, I would just say no. But as time goes on, I get more irritated by that question. That's not really the issue.

Note: Osimertinib is now funded in many provinces, including British Columbia, where Angus lives. While the option is no longer available to Angus, he is glad the treatment will help other lung cancer patients.



Stigma

The stigma experienced by patients with lung cancer is undeniable. The stigma persists, in part, because the public continues to view smoking as a bad habit rather than the serious addiction that it is. Whether patients smoked or not, they tend to be blamed for having caused their disease. For many, this blame adds an emotional burden to an already overwhelming situation. It can adversely affect the way they cope and communicate. People with lung cancer and their loved ones are often hesitant to disclose the disease to others. Many do not reach out for help for fear of being judged. As a result of this stigma, patients may experience guilt and shame, stress, fear of disclosing their diagnosis and avoidance of social situations, which leads to isolation.

The stigma surrounding lung cancer is presumptuous because:

- Smoking is not simply a bad habit. In fact, smoking is a serious addiction. For many people, especially those with less social support or few financial resources, conquering such an addiction can be very difficult.
- A genetic component may predispose certain individuals to lung cancer.
- Other factors may cause lung cancer, including exposure to radon, asbestos and second-hand smoke.

In fact, if you have lungs you can get lung cancer. This includes current smokers, those who have worked hard to quit and never-smokers. No one deserves lung cancer and yet lung cancer patients face stigma and judgment that they have a self-inflicted illness. The notion that if you don't smoke, you are worry free from cancer is a common misconception that can lead to late diagnosis and poor rates of survival. In fact, as many as 15 per cent of lung cancer patients are life-long non-smokers, and an additional 35 per cent of patients diagnosed with lung cancer have quit before the time of diagnosis.⁹

The rates of never-smokers with lung cancer is also on the rise and a re-focus of media reporting is required to align with a shifting demographic of patients being diagnosed. It is well documented that stigma is associated with negative psychosocial and medical outcomes, including delayed diagnoses, poor quality of life, poor communication between the patient and their physician and increased mortality.



You simply do not see this type of blame culture with any other disease. Lung cancer is the biggest cancer killer in the world. There is no place for a culture of blame or shame that adversely affects individuals and contributes at a broader level to poor resourcing of the research necessary to allow people to live longer and better lives after a lung cancer diagnosis. No one deserves lung cancer.”

—Dr. Matthew Peters,
Chair of The Global Lung Cancer Coalition

Lung cancer has not received the kind of media attention it deserves. When it is reported, it is usually because a public figure has died, and the person’s smoking history is often the first thing mentioned. This further stigmatizes the disease.

Another effect of stigma is that, although lung cancer is by far the largest cancer killer, it is also the least funded. Compared to others like breast and prostate, lung cancer receives only a fragment of research investment. One study comparing the burden of certain cancers relative to their funding found that lung cancer was under-funded when compared to the burden it poses on society (on incidence, mortality and person-years of life lost). The study concluded that “disease stigma negatively impacts funding.”¹⁰

Public education, as well as of healthcare providers, is the key to changing the perception and reducing the stigma associated with lung cancer, as well as healthcare provider education.

How stigma affects Canadians with lung cancer

- 42% of people with lung cancer feel less deserving of help
- 55% of Canadians who have lung cancer report social isolation due to stigma
- 45% of Canadians with lung cancer report putting off doctor visits due to self-blame

Source: The Lung Association. (2018). *Stigma Report* <https://www.lung.ca/sites/default/files/StigmaReportSeptemberFINAL.p>

**Don't ask
whether I smoked.**

**Ask how lung
cancer screening
saved my life.**

Debi's Story



In 2010, Debi Lascelle, who quit smoking 13 years prior, saw an ad calling for smokers and ex-smokers to participate in an eight-city pan-Canadian study.

“My dad died of lung cancer. So, when I saw the ad for the study, I carried it around for a while, thinking about it, and then I called,” says Debi.

That call saved her life.

As part of the Early Lung Cancer Detection Study, she had a CT scan at the Ottawa General Hospital. It showed a lesion in her right lung. It was stage IA lung cancer. On Valentine's Day 2011, she had a lobectomy to remove the 13-millimetre adenocarcinoma.

Thankfully, it was caught soon enough to give her a fighting a chance.

Debi is now 62-years-old and cancer free. She is certain that without early screening, she would likely not be here today.

“I hope that every Canadian province and territory adopts an organized, regular early screening program. We do it for breast and colon cancer, so why not lung cancer? What's more, early screening, detection and treatment of lung cancer saves money in the long run.”

With the proper screening protocols, 75 per cent of lung cancer diagnoses are at an early stage when it responds better to treatment – with dramatic cost savings to the health-care system.

Today, Debi is retired and lives with her husband of almost 30 years, John. Early screening gave them more time for love and life.

In that time, she has had to work hard to overcome the shame and guilt many lung cancer patients feel. “I have had people tell me I did this to myself,” says Debi.

“Yes, smoking is bad, but smokers are not. We deserve the same compassionate care and support as anyone with any kind of cancer.”

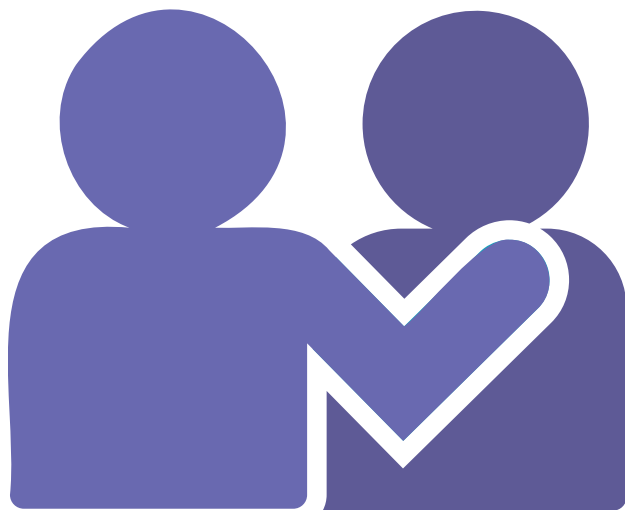
“I tried to quit many, many times. Finally, I did.”

Smoking is not simply a bad habit. It’s a serious addiction. For many people, especially those with less social support or few financial resources, conquering the addiction can be very difficult.

“When you hear of someone having a lung cancer diagnosis, rather than asking if they smoked, if nothing else, you could say, ‘I am sorry to hear that.’ Offer some empathy, some concern. We are deserving of the same care as everyone else. We deserve nothing less. I didn’t deserve cancer.”

“

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but smokers are not.
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The Need for Psychosocial Support

People living with lung cancer can experience stress, anxiety and depression. Lung cancer patients at all ages require psychosocial support. For seniors, the need for support is great because they often have other medical issues, as well as psychosocial issues associated with aging. People who are younger are diagnosed during their most productive years, when they are raising families and building careers. Family caregivers and other loved ones experience emotional distress, role changes financial burden, caregiver stress and fear of losing their loved one.

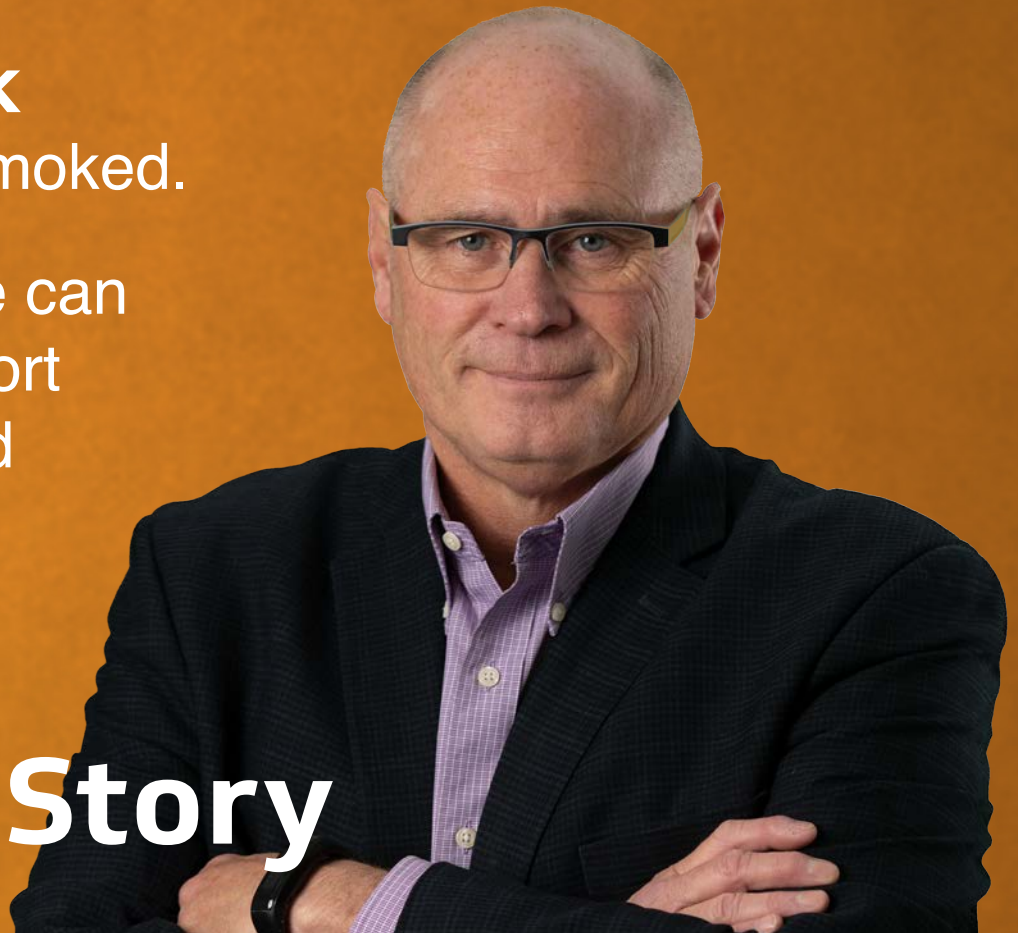
Without help to address these challenges, patients may not adhere to therapy or be less able to cope or implement healthy behaviours. Psychosocial support helps to minimize stress, improve quality of life, treat depression and anxiety and enhance coping skills. Support can include education, peer support and services from social workers and counsellors, psychologists and psychiatrists.

Patients diagnosed with lung cancer should be screened for distress using a validated tool and those with high levels of distress should be referred for an appropriate intervention. People going through treatment require support to manage anxiety and fears related to recurrence or spread, new symptoms and side effects of treatment. Counselling and education can help manage expectations, especially around what it's like to live with cancer, anticipated success of the treatment and prognosis. Patients in palliative care can be helped with counselling and information regarding how end of life care works and how it can improve quality of life and symptom management. Family caregivers and loved ones require support as well, in accessing information and to reduce caregiving stress and fears regarding their loved one's prognosis.

**Don't ask
whether I smoked.**

**Ask how we can
better support
patients and
caregivers.**

Tim's Story



'You can't have lung cancer, you have never smoked!' is the typical reaction from most," says Tim Monds who has never tried a single cigarette.

In April 2016, he went to the hospital with shoulder pain. He thought he was having a heart attack. It was lung cancer.

That June, he had an upper-left lobe lobectomy to remove the diseased section of his lung. As follow up, he went for a CT scan every three months. Everything looked good until 2018.

Just three weeks after retiring as superintendent of the Parkland School Division in Alberta, 11 new spots were discovered on Tim's lung.

Because they were all very small, the decision was made to wait and see if they remained. So, that summer, Tim and his wife of 38 years, Patty, travelled through Europe. When they returned, Tim had a middle-right lobe wedge resection to remove two of the spots.

The diagnosis for Tim – father of four and grandfather of two – was stage IV lung cancer.

The nine remaining spots have grown between one and two millimetres in the last two years – an unusually slow growth rate for lung cancer.

“I am feeling quite blessed that it is progressing slowly. I am hoping that this can continue for a long time,” said Tim. “I am told it is not curable. But with the amazing advances in medicine, I remain optimistic that it could be at least a manageable chronic disease.”

Tim leans on his family for support and finds comfort in regular meditation. Still, he says people with lung cancer need more psychological support to cope with loneliness and other challenges.

“There are fewer support groups for us. Cancer is an isolating disease to begin with. Coupled with very few support groups, lung cancer patients may feel even more isolated.”

He’s starting a support group in Edmonton to help.

“It will be a place to speak with others, share what is going on in research and learn from medical professionals about innovations and treatments. We want it to be a place to discuss how we can move forward,” Tim says.

With the support of his family, Tim began the Give a Breath Walk/Run to raise awareness and support for lung cancer – the one number cancer killer in Canada that is also the least funded. The first event raised \$35,000!

“My goal is to build awareness that lung cancer is not just a smoking cancer. I am living proof of that,” says Tim.

“But, does it really matter if you smoked or not? We should all be treated the same. We all deserve the same support and treatment.”

“

But, does it really matter if you smoked or not? We should all be treated the same. We all deserve the same support and treatment.”

Economic Costs of Lung Cancer in Canada

Lung cancer leads to costs to the health system, people living with lung cancer and their families. According to a Conference Board of Canada report, the growth expected in the number of lung cancer cases in the future, along with increases in direct costs (including drugs, hospitals and physicians) and indirect costs (including long-term disability losses and mortality) will push total lung cancer costs to \$10.5 billion by 2030.¹¹

Direct Costs

A 2019 Ontario study of a group of all-stage non-small-cell lung cancer patients over a five-year period, the total cost of care was \$1.9 billion, with a mean cost of \$76,816 per patient. Inpatient hospitalizations (\$635.2 million), cancer clinic visits (\$323.7 million) and physician services (\$301.4 million) were the top cost contributors.¹²

According the Conference Board of Canada, by 2030 the costs of hospitalization, physicians and drugs for Canadian lung cancer patients will reach \$980 million.¹³

Indirect

It is difficult for people with lung cancer to continue normally with their daily activities because of symptoms, medical appointments and treatment regimens and side effects. Many people need to take time off work to attend appointments and manage treatment. Managing appointments is even more difficult for lung cancer patients in remote or rural communities, as they may need to travel to better equipped cancer centres for the treatments they need.

The Conference Board of Canada estimate that the costs of long-term disability and mortality due to lung cancer will reach \$9.53 billion by 2030.¹⁴

Years of Life

Potential years of life lost (PYLL) is an estimate of the average number of years of life lost due to premature death. During the period from 2010-2012, the PYLL for all cancers combined was about 1.45 million, which was considerably higher than any of the other leading causes of premature death in Canada. Lung cancer represented 368,875, or 25 per cent, of the premature deaths by cancer.¹⁵

Inequalities in Lung Cancer Outcomes in Canada

Examining cancer outcomes by social and economic factors poses a challenge in Canada, given that government requirements do not mandate that this data be collected. Nonetheless, recent studies have provided some insight into this relationship. Research has shown that health outcomes for patients in Canada with lung cancer differ based on income, immigrant status, ethnicity and rurality.¹⁶

A Canadian Partnership Against Cancer study found that people living in rural and remote areas have higher incidence and mortality rates than Canadians living in urban settings. Inequities in lung cancer outcomes were also observed based on socioeconomic status. People from low-income neighbourhoods have higher incidence and mortality than those from higher income areas.¹⁷

Inequalities in lung cancer risk are in part due to factors such as higher rates of tobacco use and greater exposure to operational and environmental pollutants among lower-income and other marginalized groups. Poorer lung health outcomes are also associated with barriers to accessing services. The literature suggests that low-income communities, recent immigrants and ethnic minorities face increased barriers and stigma when accessing care. Factors such as education, linguistic barriers, personal beliefs and poor expectations of cancer outcomes contribute to inferior cancer outcomes among these communities.¹⁸

Recommendations and Required Action

Challenge 1: Diagnostic Screening & Molecular Testing

Diagnostic Screening

British Columbia recently announced that it will have Canada's first, and only, lung cancer screening program. Meanwhile, pilot studies are investigating the feasibility of implementing lung cancer screening programs for high-risk populations in several other provinces.

The aim of these programs is to detect disease at an earlier stage, when it may respond better to treatment. Currently, about 70 per cent of lung cancers are diagnosed at a late stage (stage III or IV),¹⁹ so these programs may help reduce lung cancer mortality rates.

Screening programs that detect lung cancer early are not expensive and they present dramatic cost savings to the health system. Early detection improves the cure rate and eliminates the costs of treating at a late stage, which is the more expensive stage.

The Pan-Canadian Early Detection of Lung Cancer study, published in 2014, found that the average cost to screen individuals with low dose computed tomography is \$453 per person for the initial 18 months after a baseline scan. If lung cancer is detected at an earlier stage of disease, patients can be treated with curative surgery, which costs, on average, \$33,344 per person over two years. These combined costs are significantly lower than the average cost of \$47,792 needed to treat advanced-stage lung cancer with either chemotherapy, radiotherapy or supportive care alone.²⁰ In 2016, the Canadian Task Force on Preventive Health Care released a guideline recommending annual lung cancer screening in high-risk adults ages 55-74 using low dose computed tomography.²¹ This has led to various provincial pilot projects that screen high-risk individuals, however, only one province has announced the creation of a formal lung cancer screening program.

Recommendations

All provinces and territories need to adopt consistent screening programs. Breast cancer and cervical cancer screening programs are widespread, but for lung cancer there is the need for comprehensive, low-dose CT screening programs in selected populations, which should be linked with smoking cessation programs.

Each province and territory should expand its current cancer screening program to include lung cancer screening. We recommend a joint task force be discussed and developed at a Provincial/Territorial Health Ministers Meeting. This task force would create best practices and implementation guidelines and should include health ministry representatives from each Canadian province and territory.

Molecular Testing

The first step in connecting patients with the right targeted therapies is molecular (biomarker) testing of a tissue sample from the patient's tumour. This is done in a lab setting, where a pathologist examines the tissue for biological changes in genes or proteins.

Across Canada, significant barriers prevent patients from accessing biomarker tests. A lack of funding or national funding guidelines constrain provinces from funding different biomarkers for testing and expanding testing to more centres. In addition, provincial regulatory and administrative processes have not kept up with innovations in cancer treatments. The lack of coordination and absence of standard processes and procedures cause significant regional variabilities and inequities in care.

Provincial Example: Ontario

In Ontario, the provincial government currently funds three biomarkers for testing in some capacity—EGFR, ALK, and PDL1. However, these only exist in a small number of reference centres across the province. The result is that specimens need to be mailed to outside centres with the capacity to conduct biomarker testing, causing wait times of up to six weeks. Often, patients do not live long enough to see the results of the biomarker tests. A 2017 study found that there is a lack of funding dedicated by the Ontario government towards diagnostic testing and more than 90 per cent of lung cancer patients are treated in a community setting, and these patients do not have access to timely biomarker testing.²²

Another commonly encountered barrier is Ontario's outdated and cumbersome laboratory licensing process. The process is designed for traditional genetic testing used for hereditary disorders, and is not particularly suited to cancer care. Licences are issued on a per gene basis, which ignores the fact that multiplex testing (often up to 500 genes at a time) represents the most efficient approach to testing. The process is time consuming and removes physicians from their clinical responsibilities. The system in place for biomarker testing in Ontario is insufficient to guide treatment for the majority of patients, resulting in poor care for this population and high costs to the healthcare system in managing the consequences.

Recommendations

The lack of leadership around testing from a federal perspective is preventing Canadian lung cancer patients from accessing the most effective treatments. Given the inconsistencies across the country, the fact that drug approvals fall largely under federal government purview and the need for national objectives and guidelines, we call on the federal government to lead the development of a national biomarker testing framework that can be implemented by individual provinces and territories. Similar to the national framework for COVID-19 testing and contract tracing, the provinces and territories should have the sovereignty to determine which guidelines suit them best.

Challenge 2: HTA Processes/Approvals

Pan-Canadian health technology assessment (HTA) processes must accommodate new innovations in medicine. The current process is fragmented and inconsistent, leading to extensive delays in essential drugs receiving public funding by the provinces. Many efficiencies can be found within the system to facilitate the process of drug approval.

Health Canada's 'Notion of Compliance with Conditions' (NOC/c) process allows for certain drugs to receive conditional approval on the basis that the drug company will later complete additional clinical studies confirming its benefit. Drugs are eligible for "serious, life-threatening or severely debilitating diseases or conditions" if there are no existing treatments available, or the new drug exemplifies a significant improvement compared to existing drugs.

After Health Canada grants a conditional approval, the pan-Canadian Oncology Drug Review's (pCODR) expert review committee (pERC) makes a final decision to the provinces to either recommend reimbursement, deny reimbursement or consider reimbursement once certain conditions are met. pCODR's pre submission guidelines outline the need for submitters to demonstrate efficacy, effectiveness and safety evidence. This is limited to evidence demonstrated through clinical studies, with comparison clinical studies being of particular interest. A

study conducted by Anderson et al. found that between January 2010 and March 2017, none of the drugs given conditional approval by Health Canada received recommended reimbursement by pERC. In addition, only 50 per cent of NOC/c drugs were given a conditional reimbursement recommendation by pERC. Twenty-seven per cent of these drugs were denied reimbursement on the grounds that there was insufficient evidence demonstrating their benefit in comparison to other treatment options.²³

Consider This: **FDA Accelerated Approval**

The United States Food and Drug Administration permits drugs that meet a medical need for which there are no other drug options to be approved on the basis of a "surrogate or an intermediate clinical endpoint." Drug companies are still required to demonstrate clinical benefits through subsequent confirmatory trials. However, these requirements allow for drugs for smaller patient populations where conducting randomized control trials/comparative studies are more difficult, to be approved faster. Through the European Medicines Agency Conditional Marketing Authorization Process, drugs that are found to have benefits to immediate access that outweigh any risks associated with less complete data than typically required can be approved for conditional marketing authorization. Drug companies must provide complete data by specific deadlines, which are outlined in their marketing authorization.

Recommendations

We recommend that pCODR matches Health Canada's Notion of Compliance with conditions (NOC/c) process by developing its own framework for recommending conditional funding for drugs that meet a necessary medical need.

The conditional funding framework should include clear conditions for full approval, including timelines for reassessment, similar to the European Medicines Agency conditional marketing authorization process.

Challenge 3: Treatment Accessibility and Affordability

Canada must improve the speed of approval for cancer drugs. Delays in the public reimbursement of oncology drugs have increased for all provincial and territorial public drug plans. The establishment of centralized processes of HTA and drug negotiation, including the Common Drug Review (CDR), pCODR, and the pan-Canadian Pharmaceutical Alliance (pCPA), have aided in eliminating unnecessary duplication of processes between provinces and territories. Nonetheless, we still see significant delays in provincial listings of oncology drugs, as well as discrepancies between which drugs are being funded by which provinces.²⁴

Moreover, even after certain cancer drugs are approved, there are issues around affordability. In Canada, oral cancer medication is publicly covered by all of the western provinces, Quebec and the territories. Ontario and the Atlantic provinces are lagging behind in their coverage of important cancer medications. In Ontario, oral cancer drugs are only covered under the Ontario Drug Benefit (ODB) and the Trillium Drug Program for those age 65+, receiving social assistance or with limited private insurance. In contrast, stage IV cancer drugs are publicly covered for all Ontarians because they are administered in hospital.

Consider This: Manitoba's Home Cancer Drug Program

Manitoba's Home Cancer Drug Program, initiated in 2012, allows all Manitobans to access certain publicly funded oral cancer medication. Patients must register with CancerCare Manitoba to receive coverage and be eligible for Manitoba's Pharmacare program. Covering the costs of these drugs has yielded overall costs savings to the healthcare system.

Recommendations

Lung Cancer Canada's Faces of Lung Cancer Report (2019) found that the delay from the time of Health Canada approval to provincial coverage of lung cancer drugs can range from two to upwards of five years.²⁵

Specifically to the pCPA process, studies have shown significant delays from the Canadian Agency for Drugs and Technologies in Health (CADTH) completion of HTA to the pCPA finalizing negotiations on drug prices. One report highlights that the pCPA delays are, in part, being caused by a lack of guidelines around appropriate timelines and an absence of clear negotiation criteria.²⁶

We recommend that the pCPA develop a framework for shortening timelines that includes alignment with CADTH processes. We also stress the need for provinces to examine their individual funding processes to find opportunities for parallel reviews. Two to five-year delay times for provincial reimbursement of lung cancer medications is unacceptable and threatens the lives of Canada's most vulnerable patients.

We must also improve the affordability of oral cancer drugs. For example, in Prince Edward Island, Tagrisso (osimertinib) is not currently covered by the province. At the recommended dose of 80 mg per day, Tagrisso costs \$294.67 per day, adding up to more than \$8,000 per 28-day course of treatment.

Provinces should develop a system similar to Manitoba's Home Cancer Drug Program, whereby all Canadians are able to access oral cancer drugs, regardless of age or income.

Challenge 4: Rapid-Diagnosis Assessment Programs

Rapid-diagnosis assessment programs or diagnostic-assessment programs are critical to efficiently assessing and diagnosing patients. They also provide psychosocial support to patients and help them navigate the healthcare system. These represent best practices and should be supported across the provinces and territories. Yet, rapid-diagnosis assessment programs (RDP) or diagnostic-assessment programs (DAP) are not available in all provinces.

Recommendations

It is clear that organized, centralized systems with multidisciplinary team membership are optimal for diagnostic cancer assessment services. Yet, RDP and DAP facilitated by

navigators are not available in all provinces. For example, one study found that in Ontario, the median total time for patients with lung cancer from initial presentation of symptoms to commencement of treatment was 4.5 months. This is in part due to the large amount of time taken to complete diagnostic testing. In this study of lung cancer patients, patients saw up to four specialists and were referred by multiple doctors before starting treatment.²⁷ Implementing diagnostic assessment programs would eliminate duplication and reduce the time for quality diagnosis. Provincial health organizations should carefully map out programs according to service and jurisdictional demands through strong and collaborative leadership between clinicians, clinical administrators, hospital CEOs and the local health authorities.

Challenge 5: Reducing Stigma

Steps must be taken to reduce the stigma surrounding a lung cancer diagnosis, among both healthcare providers and the public.

Recommendations

The needs of people living with lung cancer and the complexity of the disease should be included in professional training and medical workforce curriculum to promote awareness and provide strategies to shift perceptions away from stigma.

Provincial bodies, such as Colleges of Physicians and Surgeons, should be responsible for measuring and following up on attitudes of healthcare providers in lung cancer treatment.

Medical education should improve training in tobacco cessation treatment with a focus on assisting people overcome a severe addiction.

Public education campaigns, such as the Lung Health Foundation and Lung Cancer Canada's Stop Asking the Wrong Question, should be widespread across Canada to help change the public's perception of lung cancer and people diagnosed with the disease. We encourage the federal government to dedicate funding to fill the gap in lung cancer awareness as it relates to risk factors, symptoms and general awareness of the disease.

Challenge 6: Increasing Psychosocial Support

Comprehensive cancer care should include appropriate psychosocial health services to support effective communication between patients, their families and care providers; identify psychosocial health needs of patients and their families; and implement a plan that links the patient and family members with needed services.

Recommendations

All people living with lung cancer should be screened, using a validated tool, for psychosocial support needs and if appropriate, be referred to psychosocial support services as soon as possible. Those with more severe needs should be referred to psychosocial support from professionals with experience in an oncology setting. Provincial cancer organizations, such as BC Cancer, Cancer Care Ontario and the New Brunswick Cancer Network, should ensure all lung cancer patients have access to quality psychosocial support. In addition, these provincial bodies must guarantee implementation of evidence-based best practices, such as the ones below.

- Screening tools should encompass physical symptoms, emotional or spiritual distress, logistical or material needs, inadequate social supports and behavioural risk factors.
- Health care organizations should develop interprofessional collaborative care models that ensure access to the full range of psychological, physical, social, emotional, spiritual, nutritional, informational and practical services needed by cancer patients and their families.
- All cancer care providers should participate in education and training programs to increase their awareness of the significance of psychosocial care and enhance their skills in the assessment and management of psychosocial issues.
- Regional and provincial reporting should include indicators to measure the effectiveness of psychosocial care and services.

Helpful Terms and Abbreviations

Stigma: Lung cancer stigma is common. It persists, in part, because the public continues to view smoking as a “bad habit” rather than the serious addiction that it is. Whether patients smoked or not, they tend to be blamed for having caused their disease. For many, this blame adds an emotional burden to an already overwhelming situation.

Lung cancer screening: Screening means testing for a disease when there are no symptoms or history of that disease. In lung cancer, screening allows more cases to be caught early, when curative treatment is possible. Only one province, British Columbia, has formally adopted a publicly funded lung cancer screening program.

Precision medicine: Care that optimizes therapeutic benefits for certain patients based on their genetic or molecular profiles. In order to access precision medicine, the patient must first have access to molecular testing.

Molecular (or tumour) testing: Tumor testing is a promising new field in the diagnosis and treatment of lung cancer. It is referred to as molecular, biomarker or genomic testing and is a procedure to look for changes (mutations) in the tumor DNA. A piece of the lung cancer tissue is taken during a biopsy procedure and it is sent to a special laboratory that can identify the genomic profile of the tumor. Based on the result, a specific treatment may be available to target the specific mutation that exists in the tumor cells.

CADTH: The Canadian Agency for Drugs and Technologies in Health, or CADTH, is a Canadian national organisation that provides research and analysis to healthcare decision-makers.

NOC/c: An NOC/c is authorization to market a drug with the condition that the sponsor undertake additional studies to verify the clinical benefit.

pCODR: The pan-Canadian Oncology Drug Review (pCODR) is an evidence-based cancer drug review process.

pERC: The Expert Review Committee of pCODR. This group assesses the clinical evidence and cost-effectiveness of cancer drugs in order to make recommendations to the provinces and territories to help guide their drug funding decisions.

pCPA: The pan-Canadian Pharmaceutical Alliance (pCPA) conducts joint provincial/territorial/federal negotiations for brand name and generic drugs in Canada to achieve greater value for publicly funded drug programs and patients through the use of the combined negotiating power of participating jurisdictions.

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