



STIGMA REPORT

2018

BREATH
the lung association

MESSAGE FROM THE CEO

Emergency medicine responders have a saying: “we are here to help, not to judge.”

We – at the Canadian Lung Association – could not agree more. If a lung disease takes someone’s breath away, he or she should be given the same treatment – both socially and medically – as anyone else dealing with any kind of disease. Sadly, stigma plays a significant part in the physical and mental well-being of Canadians with lung disease.

The type of stigma ranges from basic misinformation and misrepresentation to blame and judgment. But the truth of the matter is – lung disease can affect anyone. Environmental, genetic and behavioural factors can all play a role in the development of a lung disease. And while we do provide support for eliminating addictions that we know are harmful to lung health – such as providing smoking cessation resources – we strongly believe that stigma and judgment simply should not have a role to play in someone’s health. The public knowledge that smoking can lead to lung disease has had the unfortunate side effect of people often getting blamed for their disease if they have smoked.



TERRY DEAN
President and CEO

We decided to conduct a survey that aims to shed light on stigma surrounding lung disease in Canada. How do people feel about lung diseases if they don’t have any? And how do those who do have a lung disease feel about the treatment they receive from others?

The following report provides an in-depth summary of our findings. Perhaps the most startling statistics were those that look at isolation as a result of external judgment or self-blame. We truly feel that we need to raise more awareness collectively about lung disease to make sure that Canadians struggling to breathe don’t have the added unnecessary hardship of social isolation and judgment to contend with. Lung disease is not a sentence that people should serve in a prison of isolation. And imposed solitude is just one of the results of stigma.



The survey also shows that 45 % of those with lung cancer delayed going to the doctor because of self-blame. This leads to unnecessarily delayed diagnoses and future complications. The goal of this report is to raise awareness and make people care about the issue. We hope that it serves as a door opener for decreased stigma, increased conversations, earlier diagnoses and a better quality of life for those whose breath has been taken away by a lung disease.

After all, those with lung disease are more than patients. They are singers, hockey players, readers and dog lovers. They are your loved ones, your neighbours and they are you.

INTRODUCTION

Lung disease has an image problem and it is time for a rebrand. Many people with lung disease have faced stigma and there is a lack of awareness about many lung disease symptoms.

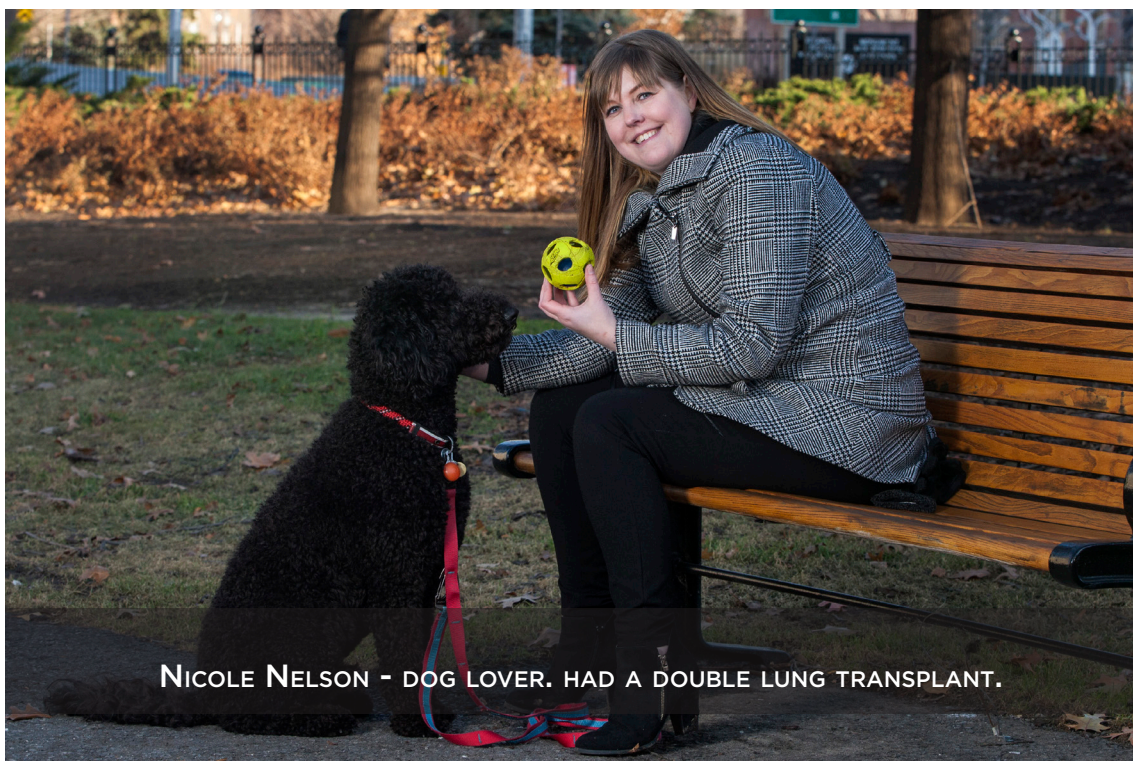
The Canadian Lung Association's recent study found that 55 % of people with lung cancer have experienced social isolation that resulted from stigma associated with their disease. Stigma also results in significant delays in lung cancer and COPD diagnoses, which results in poorer outcomes.

BACKGROUND AND METHODOLOGY

One in five Canadians is living with lung disease. Lung diseases vary from infectious diseases such as flu pneumonia, to diseases such as asthma, COPD, lung cancer, IPF (Idiopathic Pulmonary Fibrosis) and cystic fibrosis. Many people with lung disease have told The Canadian Lung Association that stigma is one of the biggest issues that we need to tackle.

The Canadian Lung Association listened and commissioned a national survey, *Lung Disease Stigma*, to gain a better understanding of the perceived notions around lung disease in Canada. An online bilingual survey of 1500 Canadians was completed between August 3 – 13, 2018, using Leger Marketing's online panel. The margin of error for this study was +/-2.5%, 19 times out of 20.

The survey asked Canadians to identify themselves as either someone with a lung disease (lung cancer, asthma or COPD), a caregiver for someone with stated disease or someone who doesn't have a lung disease. The responses then branched into corresponding questions. Of the 1500, 183 reported having asthma, 56 COPD and 23 lung cancer.



NICOLE NELSON - DOG LOVER. HAD A DOUBLE LUNG TRANSPLANT.

KEY INSIGHTS AND FINDINGS

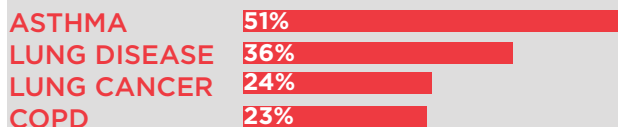
Stigma surrounding lung disease is a major barrier to accessing treatment, funding research and providing support. For instance, stigma plays a big role in providing funding for lung disease. Lung cancer and COPD are largely under-funded in comparison to their disease burden.ⁱ

Stigma also has significant mental health impacts and causes delays in diagnoses of lung disease.

WHAT CANADIANS HAVE TOLD US:

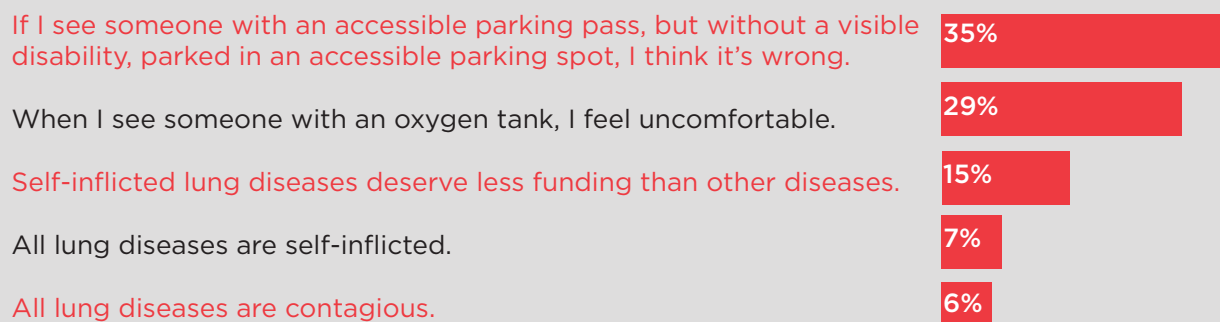
Among the Canadians surveyed, many said they know someone who lives with asthma, lung disease, lung cancer and/or COPD.

KNOWS SOMEONE WITH...



- **Nearly 1 in 3 (29%)** Canadians say they feel uncomfortable when they see someone with an oxygen tank.
- **35% of respondents** said they feel it is wrong when they see someone without a visible disability parking in an accessible parking spot with the correct pass. *Yet, many Canadians with chronic lung diseases have mobility issues accompanying their disease and require an accessible parking pass.*
- **68 %** believe those who smoke and develop COPD deserve the same sympathy as those who never smoked and developed the disease.
- **More than 1 in 7 (15%)** believe that self-inflicted diseases deserve less funding. This was especially true among ages 18-44.
- **Nearly 1 in 10 (8%)** of people with lung disease have reported they've experienced stigmatization.
- **More than 1 in 15 (7%)** believe that all lung diseases are self-inflicted. *In fact, lung diseases can affect anyone. Some have genetic predisposition, while in other cases it is behavioural or environmental factors that cause a lung disease.*

AGREEMENT (strongly+somewhat)



WHO DOES STIGMA AFFECT?



PETER CLARKE, NOVA SCOTIA
AVID READER WHO HAS COPD.

“We have to look at lung disease as any other kind of disease: as something we need to fix.”

NICOLE NELSON, SASKATCHEWAN
DOG LOVER; HAS PULMONARY FIBROSIS.

“Some people are born with lung disease. ”



KYLE CLARKE, ONTARIO
HOCKEY PLAYER WHO HAS ASTHMA.

“Lot of people assume that if you have a lung disease or any kind of breathing problems you’ve done something...where you kind of deserve it.”

KAREN LIMBERT-REMPEL, MANITOBA
MUSICIAN WHO HAS ASTHMA.

“There is some assumption out there that you can avoid lung disease if you avoid the right allergens or if you don’t smoke...I think it’s too complex to try to lay blame in any one place.”



ELIZABETH DOHERTY, NEW BRUNSWICK
MUSIC LOVER WHO HAS ASTHMA AND COPD.

“Lung disease can affect people at any age. It doesn’t pick a favourite group.”



THE STIGMA EXPERIENCE

EXCLUSION AND ISOLATION:

Lung disease can be very isolating, according to Elizabeth Doherty, young mom who has asthma and COPD. This was further supported by the findings in our survey.

- **39% of people with COPD** reported experiencing social isolation due to the stigma surrounding their disease.
- More than one-third of people with COPD reported feeling isolated and judged; seeing their friends and family less often since the diagnosis and feeling guilty and ashamed of having COPD.



THOSE WITH COPD

Feel isolated and judged

34%

See friends and family less often since diagnosis

32%

Feel guilty or ashamed of having COPD

30%

- **55% of people with lung cancer** reported experiencing social isolation because of stigma attached to their disease.
- **55 % of people with lung cancer** reported seeing friends and family less frequently since diagnosis.
- **36% of people with asthma** reported feeling left out of social activities because of their disease.

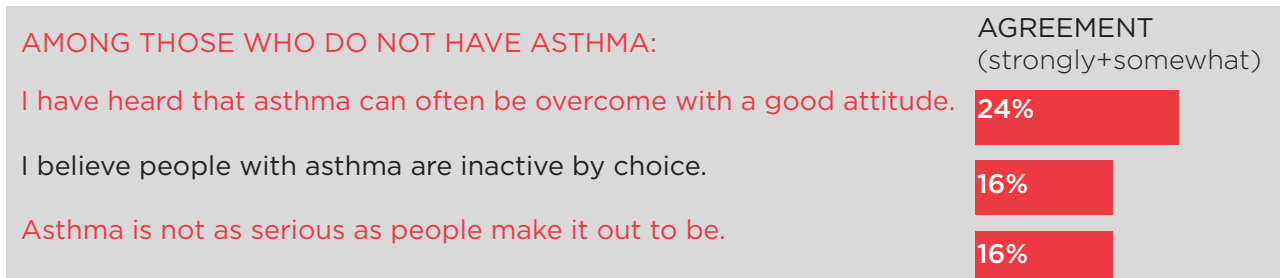
“WHEN I WAS GROWING UP,
I CERTAINLY WASN'T PICKED QUICKLY
WHEN MAKING UP TEAMS.”

-respondent with lung disease

THE STIGMA EXPERIENCE

MISCONCEPTION AND JUDGMENT:

- People with asthma seem to frequently deal with others downplaying their disease.



- More than half of those living with asthma (**53%**) reported that it has been directly or indirectly suggested to them that asthma is not a serious disease. *In reality, asthma is a serious lung disease – regardless of the type, severity and triggers of one's asthma.*
- **26% of people with asthma** reported feeling judged or stigmatized for using an inhaler in public.

“ I HAVE ASTHMA AND I HAD PROBLEMS AT WORK WHERE THE TEMPERATURE CAUSED MY ASTHMA TO FLARE UP. I WAS TOLD THAT I WAS MAKING EVERYONE ELSE UNCOMFORTABLE.”

-respondent with asthma

- The majority of respondents said they would feel sadness (**77%**) and empathy (**55%**) if someone they knew had lung cancer. However, ‘surprise’ (**50%**) was the third most reported reaction if respondents were told someone they knew had lung cancer but had never smoked.
- The stigma that lung cancer is a self-inflicted disease is quite strong as **67%** agree that people with lung cancer should have quit smoking earlier. Many also offered the question “Do you smoke?” as the first question to be asked when they find out someone has lung cancer. Others simply assumed that whoever has lung cancer likely smoked or smokes.
- **66% of people with lung cancer** reported feeling stigmatized by the view that their lung disease is self-inflicted; **46%** of those who know or care for someone with lung cancer reported the same thing about their loved ones.
- **51% of people** who have, care for or know someone with lung cancer said they have not smoked yet people assume they have and judge them.

THE STIGMA EXPERIENCE

DISEASE REALITIES: GUILT, SHAME & LATE DIAGNOSIS:

Tobacco is the leading cause of preventable disease and death. However, diseases resulting from tobacco addiction should not lead to judgment, shame and guilt. The reality is that those who smoke or have smoked often did not make an informed, conscious choice to start. Many began smoking because they were influenced at a vulnerable time in their lives by big tobacco advertising, peer pressure or family example (influenced by advertising and culture).

15% OF RESPONDENTS SAID THOSE WHO
SMOKE DESERVE LUNG CANCER



- **45% of people with lung cancer** reported putting off going to the doctor because of self-blame.
- **42% of people with lung cancer** reported they feel less deserving of help than those with other types of cancer.

11% OF RESPONDENTS SAID THOSE WHO
SMOKE DESERVE COPD



WHAT YOU CAN DO TO HELP REDUCE STIGMA

OFFER SUPPORT: If you know someone with a lung disease, ask how you can be helpful. Understand the disease and only give advice when asked.

LISTEN: Listen to your friend or family member, without judging.

LOOK TO THE PRESENT, NOT THE PAST:

It can be tempting to offer statements such as “you should have quit smoking.” However, at the time of the diagnosis, the damage has already been done. Many people are diagnosed with COPD or lung cancer years after they have quit smoking. At this point, it is important to be there for support.

INVOLVE AND ENGAGE: As our survey showed, many people dealing with lung diseases can feel isolated. Sometimes, this isolation stems from conscious or subconscious judgment or guilt, sometimes fear and sometimes poor assumptions made by others. Ask how you can engage the person in your life who has a lung disease. The physical ability, flexibility and type of engagement will vary by person.

DON'T ASSUME: It can be easy to assume that those with asthma, cannot do certain things because of our perceived notions of what might trigger them. Triggers are things that can bring on an asthma attack. Ask what triggers those around you and plan your activities with those triggers in mind.

BELIEVE: Some diseases, such as asthma, are often treated by the public opinion as a “condition” that can be overcome by a positive attitude. This can make those with asthma feel ashamed or as outcasts in the society. The representation by the media often doesn't help. The best thing you can do is believe when someone tells you his or her asthma is a serious disease.

SEE THE PERSON, NOT THE DISEASE: Public opinion, media and film sometimes form an unfortunate trifecta that creates caricatures out of people with lung diseases. These can assign negative traits or characteristics to someone based on the fact they have a specific lung disease. Whether these are that they are inactive by choice (asthma) or have smoked and thus deserve the disease (lung cancer and COPD) or a variety of others, be sure you catch yourself before you assume. The fact is lung disease doesn't pick and choose. Lung disease can and does affect anyone.

HELP FUND MORE RESEARCH: We believe those who have lung disease deserve the best possible health outcomes. You can help us fund more research that will lead to increased quality of life, treatment or cure.

VISIT LUNG.CA to learn about the different lung diseases and to donate.



B R E A T H E
the lung association

www.lung.ca