



PULMONARY HYPERTENSION
ASSOCIATION OF CANADA
.....
L'ASSOCIATION D'HYPERTENSION
PULMONAIRE DU CANADA

The Impact of **PULMONARY HYPERTENSION** on Canadians



A message from **DR. SANJAY MEHTA**



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Chair of the Pulmonary Hypertension Association of Canada*

As in many rare and fatal diseases, early diagnosis and access to effective treatment can have an enormous impact on outcomes and quality of life in patients with pulmonary hypertension (PH). This recent survey has uncovered an alarming lack of awareness of PH and its symptoms within Canada, which is contributing to the tremendous burden of illness Canadian PH patients report.

For those unfamiliar with pulmonary hypertension, it is a rare, progressive and potentially fatal lung disease in which the arteries of the lungs become narrowed by scarring, sometimes to the point of being closed. The result is high blood pressure in the lungs and, as the disease progresses, enlargement of the heart, leading to potentially fatal consequences.

In Canada, it is estimated that as many as 10,000 of our friends, neighbours and relatives have this chronic condition for which there is no known cure. Compounding the problem, the symptoms of PH are not easily recognizable or identifiable as specific to this condition. This, combined with a lack of awareness amongst medical professionals, results in a delay to proper diagnosis of two years or longer – a gap that absolutely must be shortened.

We know that we must do a better job of educating doctors, the general public and policy makers about PH to help improve and save lives; and there is no better time to start than now. Please join us in raising the awareness of PH and the needs of those living with this disease; and demanding change. We can all make a difference.

A message from **ANGIE KNOTT**



*Angie Knott, National Manager,
Pulmonary Hypertension Association of Canada*

We are grateful to everyone from St. John's to Victoria who shared their experiences living with pulmonary hypertension (PH) through this important, first-of-its-kind survey. Their insights confirm that, while some improvements have been made, many Canadians are still struggling to live with the social, emotional and financial burdens of PH. The lack of disease awareness and understanding from the public, friends and colleagues weighs particularly heavily on those affected by this disease.

In my role as National Manager of PHA Canada, I strive to fulfill our mission – to empower the Canadian pulmonary hypertension community through awareness, advocacy, education, research and patient support. With this survey, we now have a better understanding of where changes are needed most across the country to improve lives. We also hope its insights provoke thought and action among individuals and governments that will make a difference to the lives of all people touched by this disease.

As you read this report, you will hear the voices of the hundreds of people living with PH. Think about what they are saying and consider joining us in advocating for change to ensure each and every person with PH experiences the same chances, opportunities and respect that many Canadians enjoy and often take for granted.

One thing we know to be true is that we cannot bring about the changes needed for the PH community without your support. Stand with us as we ask our governments, and indeed all Canadians, to help us break down the barriers identified by the voices speaking through this survey. You can start by contacting us at PHACanada.ca or at 1-877-774-2226.

About the SURVEY

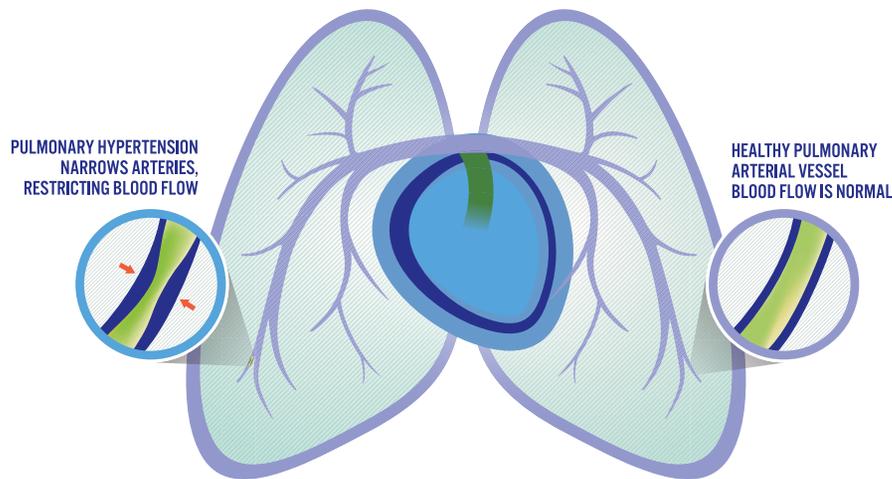
Harris Poll conducted this online Burden of Illness survey across Canada on behalf of PHA Canada between September 12 and October 25, 2013, among a total of 179 respondents (118 patients and 61 caregivers). Statistical comparisons were conducted at the 95% level of confidence between groups where base sizes allowed. The average age of the patients and caregivers who completed the survey was 51 and 47 respectively. Respondents completed online questionnaires developed by PHA Canada with the guidance of a steering committee including PH doctors, nurses, patients and caregivers. The survey was conducted by Harris Interactive and funded by Actelion Pharmaceuticals Canada Inc. through an unrestricted educational grant to PHA Canada. It is the first survey conducted in Canada to measure the impact of PH on patients and their caregivers, and has allowed a deeper understanding of PH and the physical, psychological and emotional burden the disease has on the lives of those affected by it.

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WHAT is pulmonary hypertension (PH)?

PH is a rare but potentially fatal lung disease in which the arteries of the lungs become narrowed by scarring, sometimes to the point of being closed, resulting in high blood pressure in the lungs. As the disease progresses, a person's heart can become enlarged, leading to potentially fatal consequences. PH is a chronic condition and there is no known cure.



People with pulmonary arterial hypertension (PAH) – the most severe form of PH – **live only an average of two to five years after diagnosis if left untreated.**

WHO does PH affect?

It is estimated that more than 5,000 Canadians have been diagnosed with PH but as many as 5,000 more may be affected by the condition.

This invisible disease can strike at any time and has no regard for race or age. Physical symptoms can include:

- ▶ **Breathlessness** or shortness of breath, especially with activity.
- ▶ **Fainting** and/or feeling tired all the time.
- ▶ **Lightheadedness**, especially with activity, such as climbing stairs.
- ▶ **Swollen ankles, legs, or abdomen.**
- ▶ **Chest pain**, especially during physical activity.
- ▶ **Blue lips and/or fingertips.**



DIAGNOSIS



PH is often not diagnosed in a timely manner because its early symptoms are subtle, and can be confused with those of many other conditions. As a result, many people have PH for too many years without knowing it and this progressive disease can become life threatening if not managed.

To establish a diagnosis of PH and to assess its severity, a series of tests are performed to show how well a person's heart and lungs are working. These tests may include:

- ▶ **Echocardiogram** (ultrasound of the heart).
- ▶ **Right heart catheterization** (direct measurement of pressure in the pulmonary arteries and a test of how well the heart is pumping blood to the body).
- ▶ **Pulmonary function tests.**
- ▶ **Chest x-ray, EKG, etc.**

DIAGNOSIS *delays*

The survey reveals that patients and their healthcare providers often don't recognize the symptoms of PH as indicative of a serious disease.

- ▶ In many surveyed patients, the time from **first symptoms to diagnosis was two years or longer.**
- ▶ 51% of patients surveyed state that their **family doctor did not initially recognize the symptoms of PH** and thus did not direct them into the various routes for PH-specific care.
- ▶ Patients surveyed seem to down-play major symptoms, suffering an average of 31 and 44 months with **breathlessness/dyspnea and tiredness/fatigue** before seeking medical attention.
- ▶ **Irregularities in heartbeat, fainting and chest pain** are also symptoms patients live with before seeking a medical opinion at 30, 25 and 19 months respectively.



51% of patients surveyed stated that their **family doctor did not recognize the symptoms of PH.**



In many surveyed patients, the time from first symptoms to diagnosis was **two years or longer.**

PHYSICAL burdens

Even with currently available treatments, the survey reveals that PH takes a significant physical toll on the majority of patients and caregivers, limiting their ability to work and perform day-to-day activities.

- ▶ The large majority of patients (85%) surveyed experience **some symptoms or limitations with every-day activities**, ranging from mild to severe.
- ▶ Of the patients surveyed, 78% have at least **some difficulty climbing a flight of stairs** and 55% have at least **some difficulty walking a short distance**; nearly one in five (19%) find it **difficult to have a telephone conversation**.
- ▶ More than one in five (22%) patients surveyed are **unable to be fully intimate with their partner**, due to their PH.
- ▶ More than 40% of patients surveyed report **frequently suffering from fatigue, low energy and breathlessness**, while another 37% suffer from **sleep disorders**.



SOCIAL impacts

The majority of Canadians surveyed who are living with PH experience social isolation and relationship issues, which they attribute to the “invisibility” of the disease.

- ▶ Social isolation caused by a **lack of understanding of the disease** among friends and colleagues is a primary concern for a majority of PH patients (63%) and caregivers (54%) surveyed.
- ▶ Both patients (71%) and caregivers (61%) reported feeling isolated or excluded from society because **PH is not a “visible” disease**.
- ▶ Nearly 7 in 10 PH patients report **great difficulty playing with their children or grandchildren**, or helping them with homework.
- ▶ Caregivers spend nearly 50% of their time on **activities related to caring for their relative with PH**.
- ▶ Nearly one in four patients surveyed say **their role in personal relationships** with their partner/spouse (24%), friends (23%) and within their family (22%) has changed due to their PH.



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FINANCIAL *impacts*

The survey reveals that PH also takes a significant financial toll on a large majority of patients and caregivers, many of whom are in their prime earning years, by limiting their ability to maintain employment.

- ▶ Nearly 60% of patients surveyed say **they can either no longer work or have partially stopped working** due to their PH.
- ▶ Nearly 40% of **caregivers have been forced to make changes** to their employment to care for someone with PH.
- ▶ Nearly 90% of patients surveyed say that **their income has decreased by more than 25%** due to their PH-induced change in employment; nearly half say it has decreased by more than 50%.
- ▶ But treatment can help, as nearly 20% of patients surveyed reporting they can **manage to maintain employment without difficulty once on treatment**.

50%

Nearly half of patients surveyed say that **their income has decreased by more than 50%**.



TREATMENT *gaps*



Innovative new therapies that are now available in Canada or are under investigation in clinical trials are bringing hope to PH patients for better outcomes and improved quality of life.

But more must be done. **YOUR help** is needed to improve the lives of Canadians living with the invisible disease, pulmonary hypertension.

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One-third of patients surveyed report there are **insufficient medication options to manage their PH**.

How can you **HELP?**

Contact us at 1-877-774-2226, by mail (below) or visit PHACanada.ca to learn more about PH and what you can do to help ensure those living with this disease have access to prompt diagnosis, care, treatment and support in Canada.



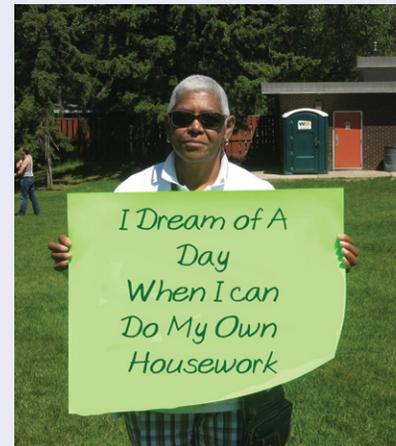
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