



PULMONARY HYPERTENSION
ASSOCIATION OF CANADA

L'ASSOCIATION D'HYPERTENSION
PULMONAIRE DU CANADA

The Socioeconomic Burden of **PULMONARY ARTERIAL HYPERTENSION** in Canada



Thank you to everyone who completed The Socioeconomic Burden of PAH Survey. The stories shared will help create a better future for everyone affected by PAH.

All photos in this report have been provided with consent.

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www.phacanada.ca

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A Message from PHA Canada

In 2021, the Pulmonary Hypertension Association of Canada (PHA Canada) undertook a comprehensive survey to examine pulmonary hypertension (PH) 's multifaceted impact on Canadian patients, their caregivers, and healthcare professionals. With over 400 respondents, primarily pulmonary arterial hypertension (PAH) patients, the survey illuminated the substantial burdens the PH community faces, from diagnostic challenges to daily life impacts. Key findings revealed significant physical limitations, relationship changes, social isolation, and financial instability as direct consequences of living with PH. Notably, employment status and income generation were adversely affected, with a significant number of patients and caregivers reporting negative impacts on their mental and emotional well-being.

The survey also highlighted dissatisfaction with available PAH treatments, pointing to a dire need for more options and improved quality of life. In 2023, a follow-up study, "The Socioeconomic Burden of Pulmonary Arterial Hypertension in Canada," further explored PAH's financial and employment consequences. Conducted by PHA Canada and the Canadian VIGOUR Centre, this study used the Work Productivity and Activity Impairment (WPAI) questionnaire to assess workplace and daily activity limitations among PAH patients.

Key outcomes from the 2023 study underlined PAH's detrimental impact on employment and financial stability, with only 28% of surveyed patients being employed and a significant portion relying on government support or facing challenges in accessing necessary medical care due to financial constraints. The severity of PAH was directly correlated with increased workplace and activity limitations, heightened reliance on caregiving support, and escalated out-of-pocket expenses.

A Message from PHA Canada

These studies collectively underscore the urgent need for enhanced awareness, better treatment options, and comprehensive support mechanisms to alleviate the burdens faced by the Canadian PH community and improve the quality of life for those living with PAH. We hope this report inspires you to join us in addressing these challenges and creating a better life for all Canadians affected by PH.



Dr. Lisa Mielniczuk
Chair, Board of Directors
Ottawa, ON



Jamie Myrah
Executive Director
Vancouver, BC

What is PH/PAH?

Pulmonary hypertension (PH) is characterized by high blood pressure in the pulmonary arteries, the blood vessels that carry blood from the heart to the lungs. This increased pressure is often caused by narrowing or blockages in these arteries, leading the heart to work harder and potentially resulting in heart failure. PH is a serious and potentially life-threatening disease.

Pulmonary hypertension (PH) is not a single disease. The World Health Organization (WHO) has identified five distinct groups based on the different causes of PH and how it is treated. One specific type of PH is pulmonary arterial hypertension (PAH), caused by the narrowing of the pulmonary arteries. The exact cause of PAH is poorly understood, but it involves the multiplication and growth of cells in the artery walls and scar tissue formation. Ongoing research has identified various biological abnormalities that contribute to PAH, including genetic factors, proteins, and other substances in the body.

PAH is a broad category that includes different subtypes, such as idiopathic (of unknown cause), heritable (genetic), and associated with connective tissue diseases (i.e., scleroderma and lupus) or other conditions. Each subtype may have its own specific causes and treatment approaches.

Who Does PAH Affect

It is estimated that over 2,000 people in Canada have been diagnosed with PAH, but as many as 4,000 may be living with the condition. PAH can strike anyone regardless of age, sex, or social/ethnic background but most commonly affects women between the ages of 30-60.

The Impact of PH on CANADIANS

In 2021, PHA Canada conducted the Canadian PH Community Survey to assess the physical, social, financial, emotional, and psychological impacts experienced by the Canadian PH community. Over 400 patients (67% of whom were PAH patients), caregivers, and healthcare professionals completed the survey, highlighting the challenges faced by those living with PH, from the journey to getting an accurate diagnosis to the impact of PH on daily life.

The survey demonstrated the significant physical burden of PH on patients, including limitations to daily activities, reduced independence, and changes to intimate relationships. Patients and caregivers experience substantial changes in their relationships and increased social isolation due to a lack of understanding and awareness of PH among friends, colleagues, and the public.

PAH patients and caregivers also reported negative impacts on their financial stability, with nearly half of patients (45%) and a third of caregivers (37%) surveyed reporting that PAH had negatively impacted their employment status and their ability to earn an income. Both patients (40%) and caregivers (44%) reported the need to take one or more temporary leaves from work or school due to a PAH diagnosis. This resulted in a financial strain significantly impacting patients' (43%) and caregivers' (40%) mental and emotional well-being.



“I didn’t want to go back to my cubicle and act like my life hadn’t just been turned around. Instead, I took months off to adjust to new medications and figure out the limitations of this body I was no longer familiar with. To some, it may have seemed like an extended vacation, but it was full of tears, bad reactions and having to prove to insurance companies that I was still sick every month.”

- Kaitlyn Salonga



“Pulmonary arterial hypertension has been the hardest thing I have had to learn to live with. It has taken my life from me as I knew it. It has changed how I parent. It has changed my ability to be a wife. It has changed my want to be social because of how hard it is. Being oxygen-dependent makes travel near impossible. I’m too young for this. 42 is not old.”

- Anonymous



When we first went into hospital, I was Mom. The second, the diagnosis came in. I was no longer mom, I was caregiver. I felt like I lost my career, which I loved because I love working with people, and that was hard for me. I just felt like I didn't have a purpose anymore, it was ripped away for me.

- Jessica Marks-Cullum



As my wife's PAH has progressed, her need for a caregiver has increased exponentially. I have to go back to work but it's not easy finding an employer who will pay what I need to earn and allow the flexibility for me to attend her various appointments.

- Don Downey

PAH Treatment GAPS

Many medications are approved in Canada to treat PAH, helping to alleviate symptoms and improve functioning and quality of life. Medical treatment can also slow the progression of PH and improve heart and lung function; however, they are not a cure for PAH.

In 2021, patients and caregivers:



62%

believed that there need to be more treatment options for PAH



57%

felt overall improvement in quality of life was the most important thing they were looking for in PAH treatments



20%

reported that their treatment side effects had gotten in the way of achieving optimal treatment

The Socioeconomic **IMPACT OF PAH**

In 2023, PHA Canada conducted a new survey to explore further the financial and employment impacts of PAH in Canada. The Socioeconomic Burden of Pulmonary Arterial Hypertension in Canada study was conducted from August 15 to September 10, 2023—the research aimed to understand how PAH affects patients’ work and daily activities. Workplace- and activity-related limitations were assessed using the Work Productivity and Activity Impairment (WPAI) questionnaire. Additionally, the survey captured data about patients’ need for caregivers and the impact of supporting a patient with PAH on caregiver work productivity.

Adult patients (18 years+) with self-reported Group 1 PAH were invited to complete the survey online. The survey was available in French and English and was promoted widely by email and multiple media channels. In the end, 217 patients met the inclusion criteria for participation in the study.

The study was conducted by PHA Canada and the Canadian VIGOUR Centre, a research group at the University of Alberta, and made possible through the financial support of Merck Canada Inc. The Principal Investigator was Dr. Jason Weatherald. The study was approved by the University of Alberta ethics board.

Who responded



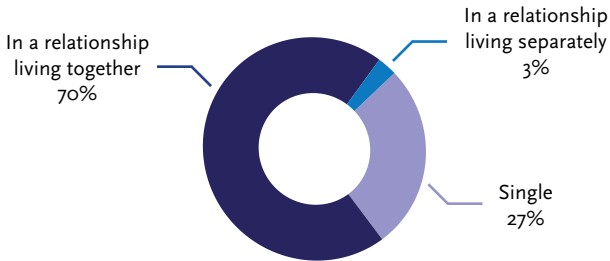
217
Patients

Who Completed the SURVEY?

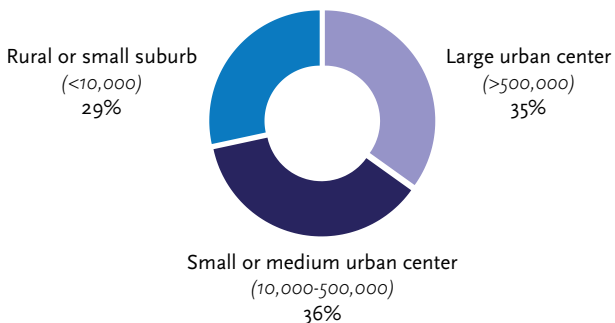
Age/Gender

Average age	57 years old
Women	83%
Men	16%
Non-binary	1%

Relationship Status

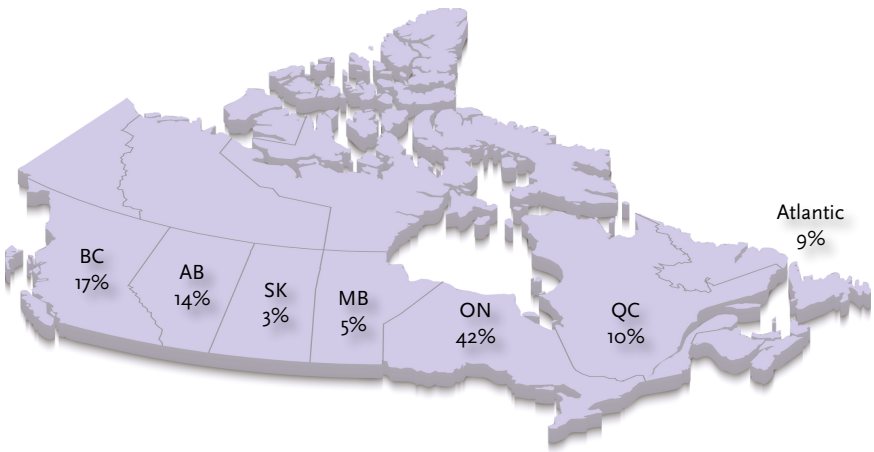


Type of Location

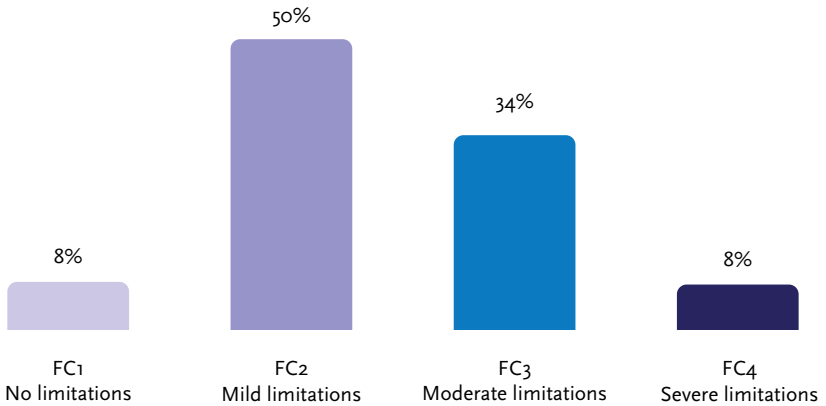


Who Completed the SURVEY?

Location

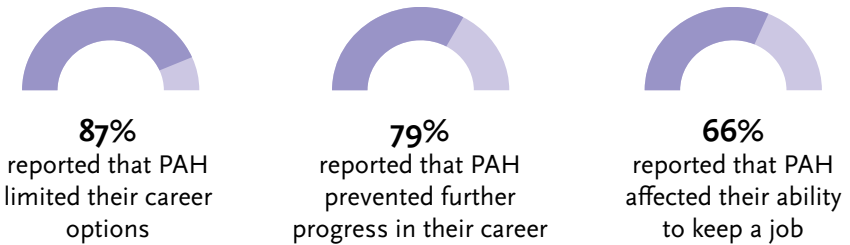


Functional Classes Reported by Patients

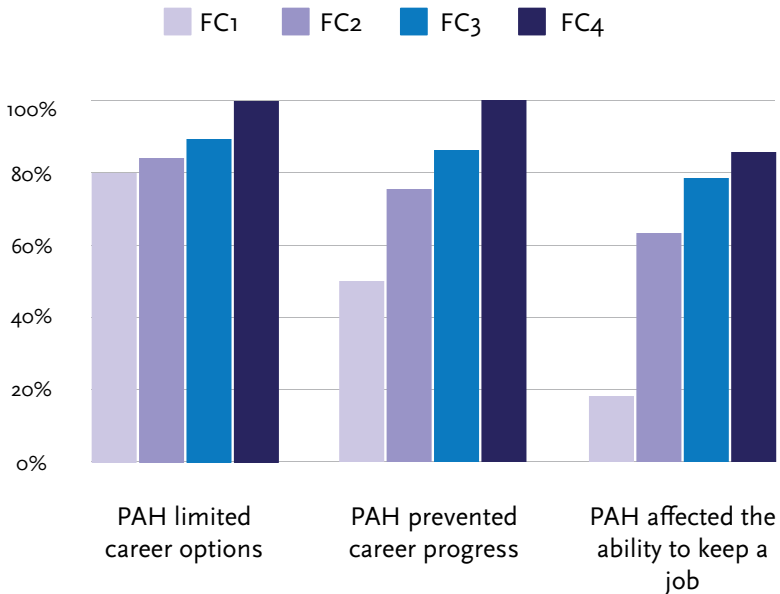


Employment IMPACTS

PAH can significantly impact a patient's ability to find and keep a job. For younger patients at the start or middle of their careers, PAH can also negatively impact their career advancement, preventing them from earning higher incomes. As demonstrated below, as the severity of PAH increases, the impact experienced by patients also increases.



Impacts on career by functional class (FC)



Employment **IMPACTS**

Changes in work patterns due to PAH:

61%

of respondents lowered their hours at work

48%

of respondents considered quitting their job

46%

of respondents had taken early retirement

45%

of respondents had voluntarily stopped (quit) working at their job

45%

of respondents changed from full-time to part-time work

43%

of respondents received financial support from the government

26%

of respondents turned down a promotion

Workplace Productivity IMPACTS

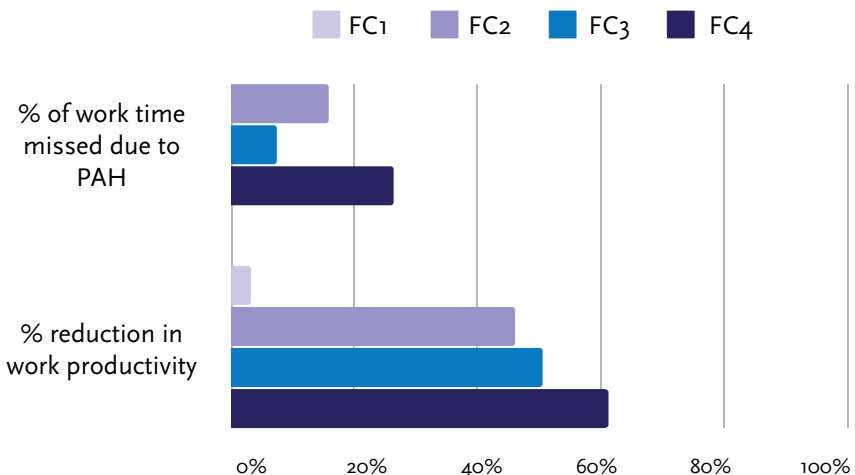
Only 28% of patients surveyed were employed, while 70% were not working, and 2% did not specify their work status. Of those not working, 50% were retired, and 29% reported being disabled.

Working patients frequently reported reduced working hours and diminished productivity at work:

- Workers reported missing an average of 12% of their work time
- Workers reported a 42% reduction in their work productivity
- Workers reported missing an average of 5 hours of work during the past seven days due to problems associated with their PAH (i.e., sick days, going in late/leaving early, etc.)

The effects on workplace attendance and productivity significantly increase as the severity of PAH increases.

Work productivity by functional class (FC)



Workplace Productivity IMPACTS

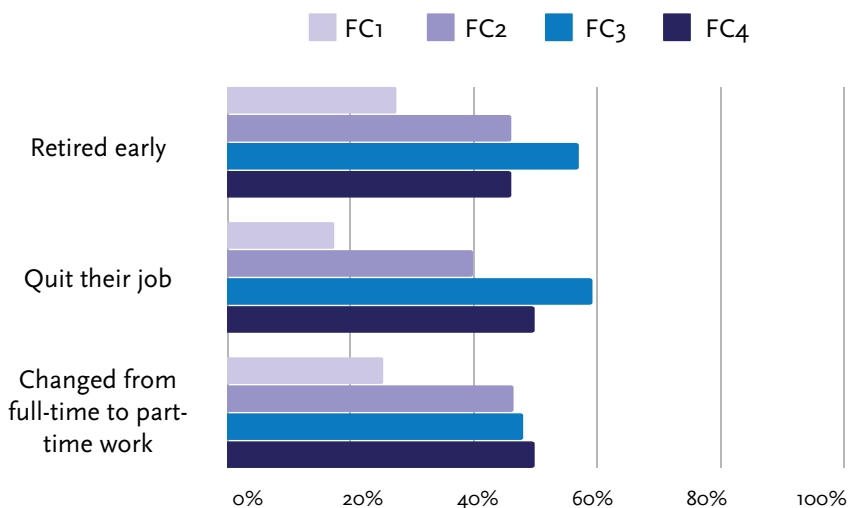
Patients younger than 65 experienced more frequent changes to their work patterns than older patients. Conversely, older patients were more likely to have resigned from work or taken early retirement.

Changes in work patterns due to PAH

As a result of PAH:	All Patients	Under 65 years	65+ years
Lowered hours at work	61%	69%	43%
Taken early retirement	46%	40%	60%
Voluntarily stopped (quit) working at one's job	45%	41%	54%
Changed from full-time to part-time work	45%	51%	29%
Turned down a promotion	26%	33%	9%
Been let go or laid-off from one's job	13%	15%	8%

The effect on patients ability to work is significantly impacted by the severity of their PAH.

Work patterns by functional class (FC)

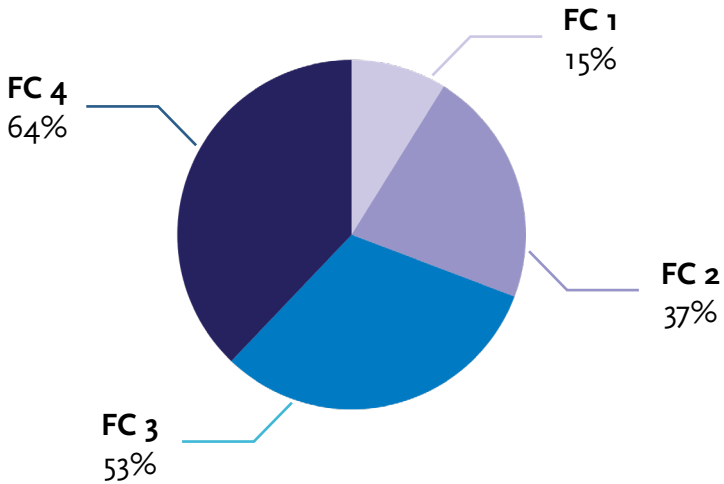


Financial IMPACTS

PAH can significantly impact the financial health of patients and their families. Reduced time spent working and early exiting from the workforce means that PAH patients must rely on other sources of income and support. Overall, 43% of patients reported they had received financial support from the government. This need for government support grew with the severity of their PAH.

Patients also reported challenges accessing their prescribed medication as a result of their financial situation. Nearly 1-in-10 respondents reported not taking medication prescribed for their PAH because it was too expensive.

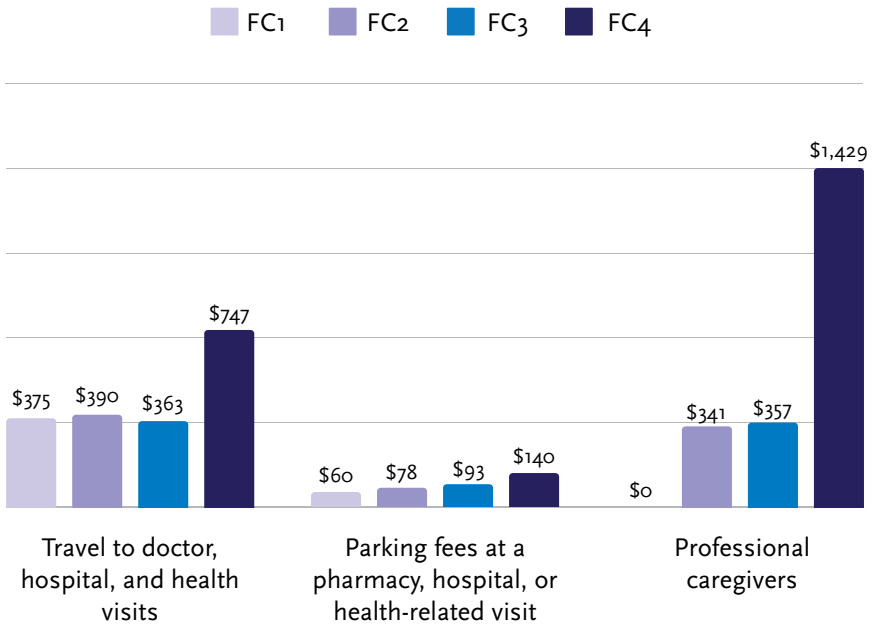
Need for government financial support by functional class (FC)



Financial IMPACTS

PAH patients must budget for many out-of-pocket expenses, including travel to clinic appointments, parking, and professional caregiver costs. As expected, these costs only increase as their functional class increases, and they become more limited in their daily activities. Reliance on professional caregiving services increases dramatically for the most severely affected patients.

Annual out-of-pocket expenses by functional class (FC)



Quality of Life IMPACTS

Amidst the struggle of coping with a wide range of physical symptoms associated with PAH, patients are also faced with the shock and often despair of being diagnosed with a rare, life-threatening condition. Like other chronically ill patients, fear, anxiety, loneliness, and depression are everyday experiences.

The majority of respondents (88%) believed that PAH negatively impacted their emotional or mental well-being, with 38% indicating a significant effect on their emotional or mental health. Women were more likely to report that PAH affected their emotional or mental well-being, at 40%, compared to 25% for men. Women were also more likely to report lacking access to a mental health provider to help manage PAH-related emotions.

Patients who reported needing help with PAH-related emotions but who lack access to a mental health provider



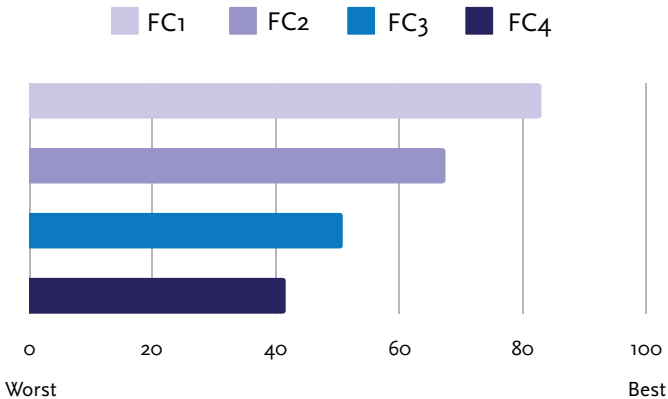
Women (65%) and men (63%) were equally likely to seek information about PAH from patient associations, but women were nearly twice as likely as men to learn from other PAH patients (49% versus 27%). PAH patients living alone were also more likely to rely on education support from their PAH peers (47% versus 39%).

Quality of Life IMPACTS

PAH patients often find socializing difficult, due not only to the physical impacts of their condition but also because of a lack of understanding from others. Just over half of respondents (56%) felt that other people avoided or distanced themselves because of PAH.

Not surprisingly, an increase in functional class was also related to a decrease in health-related quality of life. When asked to rate their health on a scale from 0 (the worst health you can imagine) to 100 (the best health you can imagine), patients in higher functional classes felt that their health was worse than those in lower functional classes. Health-related quality of life was similar across age groups and by sex.

Health-related quality of life by functional class (FC)



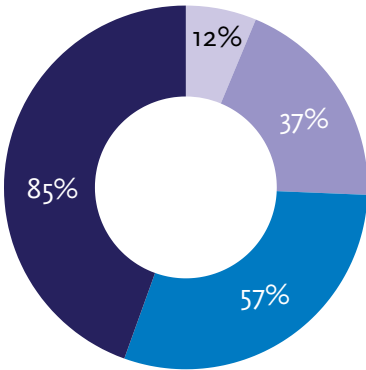
Caregiver IMPACTS

As the severity of PAH increased, patients became increasingly reliant on caregiver support. 45% of respondents indicated that due to their PAH, they currently require the help of a caregiver. Patients reported that their caregivers are most often their partner/spouse (77%) or their children (29%).

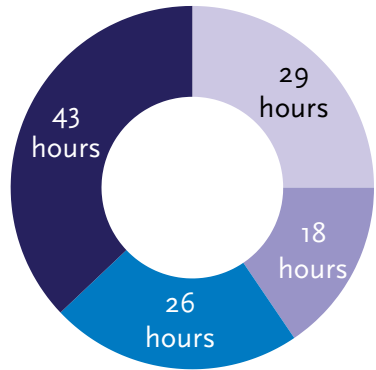
As expected, the percentage of patients requiring caregiver assistance with daily activities and the required hours increased as functional class worsened.

Caregiver assistance by functional class (FC)

FC1 FC2 FC3 FC4



Percentage of patients requiring assistance with daily activities

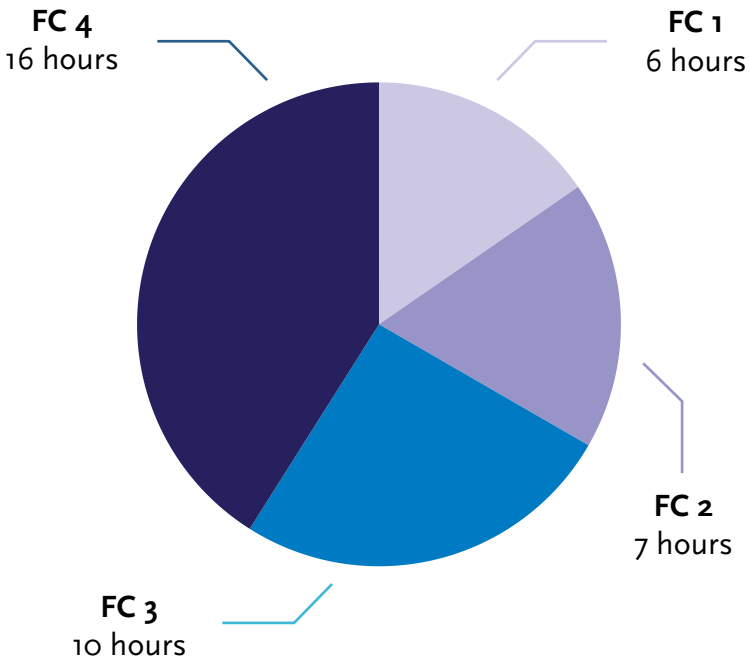


Number of hours caregivers spent per week helping with daily activities

Caregiver IMPACTS

As it was for patients, as functional class increased, caregivers also reported decreased workplace productivity as they focused more on caring for their loved ones. Caregivers lost an average of 9 hours per week of work time due to caring for their loved one with PAH.

Lost work hours for caregivers by functional class (FC)



How Can You **HELP?**

Each individual navigating the challenges of a PAH diagnosis has a unique story to tell, reflecting the diversity of experiences within this united community. However, amidst this diversity, there is a common thread: the fundamental need for equitable and timely access to high-quality care. Decision-makers, healthcare providers, and the public must unite collectively to raise awareness about PAH, expedite diagnoses, and ensure that every individual across Canada receives the best possible treatment and support.

We need your help. Contact us by email, phone, or mail (below) or visit us online to learn more about PAH and what you can do to improve the lives of families living with pulmonary arterial hypertension.



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Instagram



Facebook



X (formerly twitter)



LinkedIn



Youtube




“We already knew that patients with pulmonary arterial hypertension can face challenges in completing daily tasks and maintaining employment. This can lead to financial pressure and stress for patients and their families. In this study, we wanted to dig deeper to better understand exactly how PAH affects employment, career development, and productivity. This information can be a critical baseline to convey how PAH affects people’s lives beyond just the symptoms and signs of disease.”

Jason Weatherald, MD, MDC, FRCPC
Principal investigator, Socioeconomic Burden of
Pulmonary Arterial Hypertension in Canada



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