

BREATHLESS *for* CHANGE

Living with Pulmonary Fibrosis in Canada

2022 INSIGHT REPORT

*Naomi Matsushita, Toronto.
Meet Naomi and other people
living with PF on the back cover.*



**Canadian
Pulmonary Fibrosis
Foundation**

A message from CPFF's Board Chair and Executive Director

Since we last checked in with pulmonary fibrosis patients and their caregivers in 2020, we've all been challenged with the restrictions, fears, and sometimes the grief, of living through a global pandemic. For the people in our community, these challenges have been exacerbated by being part of a vulnerable population and living with a deadly lung disease.

This spring we asked Canadians living with pulmonary fibrosis to complete a survey about their experiences, its impact on their life and what they need for the future. More than 640 people living with PF and their caregivers from across the country responded to our call. Our heart-felt thanks to everyone who participated!

It is no surprise that many of our respondents felt worse off in 2022 than they did in 2020. In general, patients feel less able to manage their disease, caregivers are more stressed and depressed, visible minorities feel invisible to the health care system and access to timely oxygen therapy is an issue.

Breathing should be a natural right, yet 20 per cent of respondents did not get an oxygen therapy prescription when needed. Six in 10 reported that supplemental oxygen had a large negative impact on their lives and more than one third have no backup oxygen in the event of a power failure.

In addition, one in five people need, yet do not receive, counselling or emotional support and one in six are in need of, yet do not receive, physiotherapy and palliative care. Overall, one third of respondents don't feel they have effective care, and among visible minorities that number rises to fifty per cent. While some of these increasing gaps in care during the past two years may be attributable to the pandemic, it cannot account for them all.

IN THE COMING YEAR, CPFF WILL FOCUS ITS ADVOCACY EFFORTS ON ENSURING PEOPLE WITH PF HAVE ACCESS TO THE OXYGEN THERAPY THEY NEED, WHEN THEY NEED IT, REGARDLESS OF WHERE THEY LIVE IN THE COUNTRY.

We will advocate for the expansion of PF rehabilitation with existing COPD rehabilitation centers, mental health, PF exercise classes, support groups for patients and caregivers and reimbursement of oxygen therapy and the associated equipment.

We'll ramp up our resources and support for people living with PF and their caregivers. We'll actively reach out to indigenous and visible minority communities. Our new website and enhanced online channels will help the PF community stay informed and connected. We'll raise the bar on public awareness to generate widespread support and help people experiencing symptoms to self-advocate.

We will never stop fighting for you. Because Breathing should never be hard work.©



Kirk Morrison
Board Chair



Sharon Lee,
Executive Director



What *is* pulmonary fibrosis?

Pulmonary Fibrosis (PF), is a rare disease in which the lungs become scarred. Over time, normal lung tissue is destroyed, rendering them unable to provide the body with sufficient oxygen. Although currently there is no cure, many people living with PF can be helped with proper treatment and for some, lung transplantation.

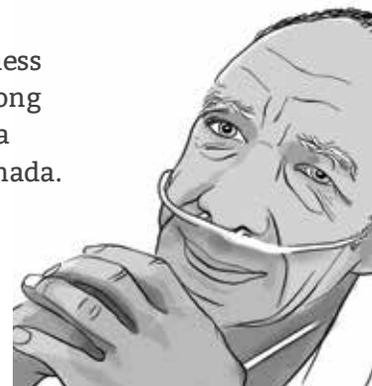
What are the symptoms?



Progressively worsening shortness of breath accomplishing tasks requiring exertion and/or a persistent cough are common.

Many patients face barriers.

PF suffers from limited awareness among the public and even among healthcare professionals, with a patchwork approach across Canada. Too many patients face years-long delays in accessing specialists due to unequal access to respirologists across the country and/or needed referrals from primary care physicians. Visible minority patients report even greater barriers to accessing care. *Learn more: cpff.ca*

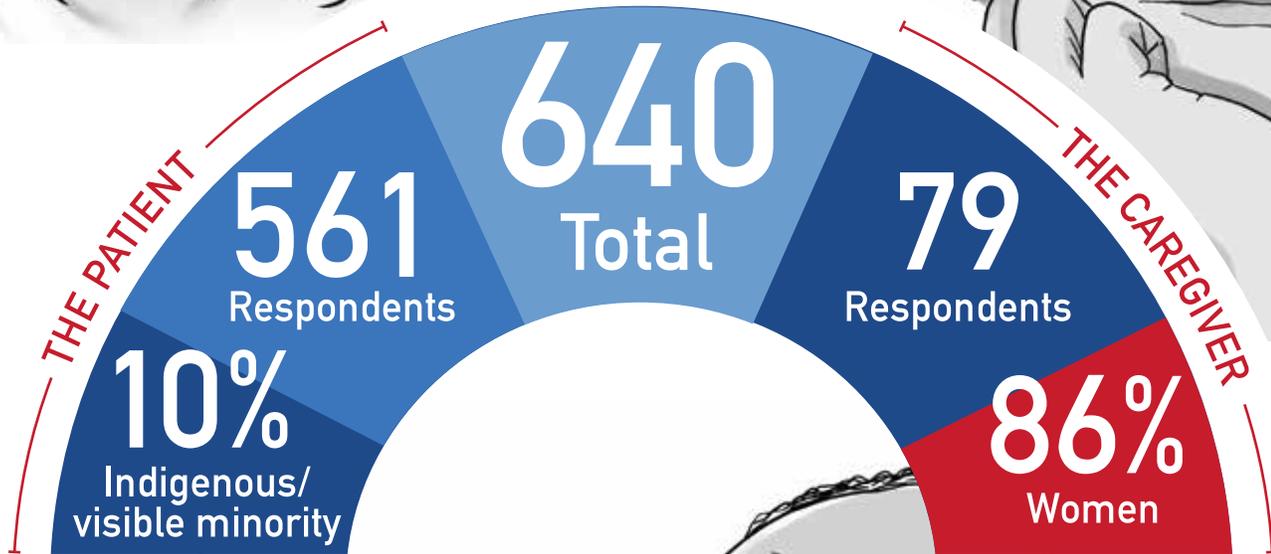


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“It took the medical system one year to get the testing done so I could get oxygen.”



“It has left me feeling useless. I have no strength to do things.”



“Mental health support is needed for both the patient and the primary caregiver.”

INSIGHT MATTERS

A lot has happened since we conducted our last patient and caregiver survey in 2020. Faced with a global pandemic, our already challenging healthcare landscape has gotten worse. Needs have *increased* even as resources have *decreased*.

To all who participated, a heart-felt thank you for your invaluable insight.

Objectives & Methodology

CPFF's objective with this survey was to provide insights and compare with 2020 findings to help us advocate for better support, treatments and access to care for patients and caregivers living with PF. Participants were asked to complete an online survey to provide insight into:

1. Patient and caregiver disease experiences and its impact on their lives
2. Experiences with available treatments and desired outcomes with new treatments
3. Experiences with supplemental oxygen
4. Types of support patients and caregivers are looking for
5. Experiences of under-represented communities to determine how they can be better served
6. Changes in diagnosis, treatment, and quality of life versus previous survey



KEY HIGHLIGHTS

Patient & caregiver quality of life has gotten worse since CPFF's last survey in 2020. Diagnosis, access to vital info and treatments – especially oxygen therapy – have all been negatively impacted.



1

DIAGNOSIS IS STILL LAGGING

- Obtaining an initial diagnosis in a timely manner is still an exercise in frustration.
- Delays between symptom onset & diagnosis have increased.
- Many patients wait years to access specialists.

2

VITAL INFORMATION IS NOT FORTHCOMING

- Many respondents lack the information they need at every stage of their PF journey.
- Many are exhausted by a constant search for information, especially about treatment options and exercise.
- Some feel neglected by doctors who are difficult to access and/or reluctant to discuss their disease progression.



3

IMPACT ON LIFE HAS WORSENERD

- Negative impacts have increased across every metric since 2020 for people living with PF.
- Nearly one in three patients are fearful, angry, or depressed – a significant increase since 2020.
- 33% of Caregivers feel hopeless and/or depressed – a 5% increase over 2020.



4

TREATMENT ACCESS IS STILL INCONSISTENT

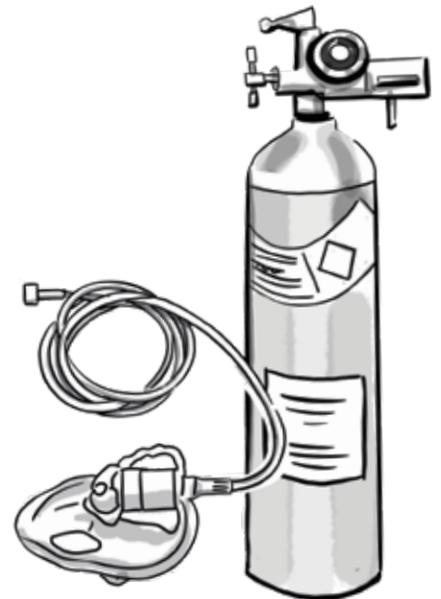
- Many feel they are not doing well with their current treatment.
- Needed treatment is out of reach for some.
- A significant portion of respondents are unable to access the mental health and counselling supports they need.
- Visible minority respondents face additional barriers to care.



5

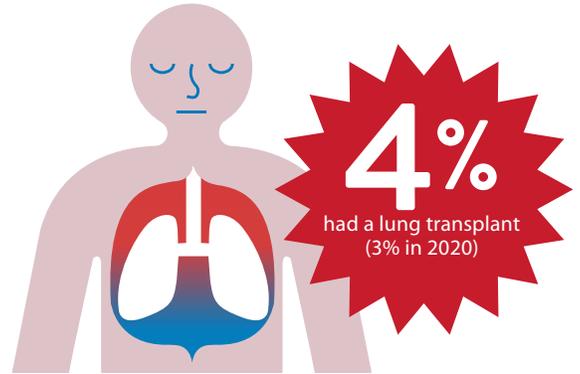
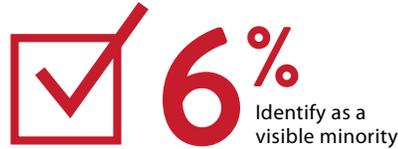
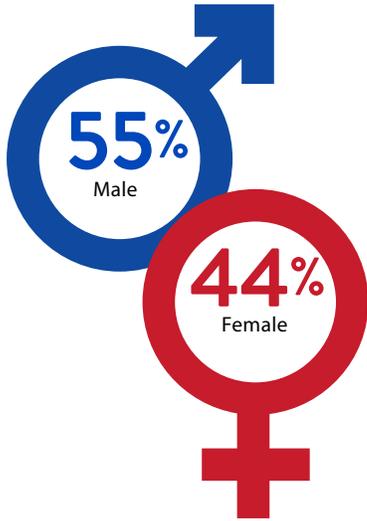
OXYGEN IS UNACCEPTABLY SCARCE

- One in five pulmonary fibrosis patients experience delays in accessing oxygen.
- Too many patients did not get an oxygen therapy prescription when needed.
- Some patients face financial barriers to access oxygen.
- Access to sufficient oxygen varies widely depending on where the patient lives.



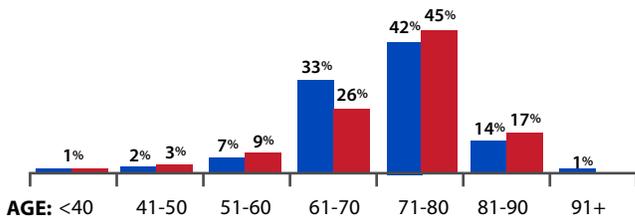
THE PATIENT

Since 2020 conditions for people living with PF have gotten worse.

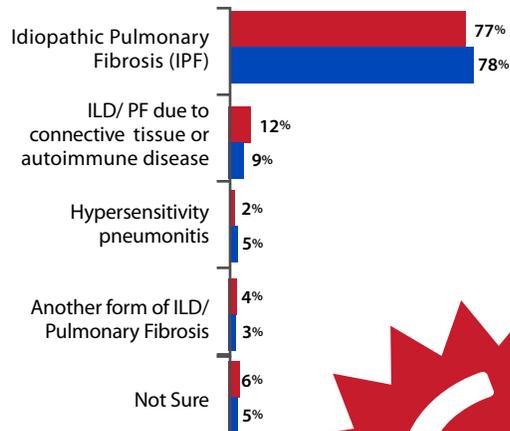


2020 VS 2022

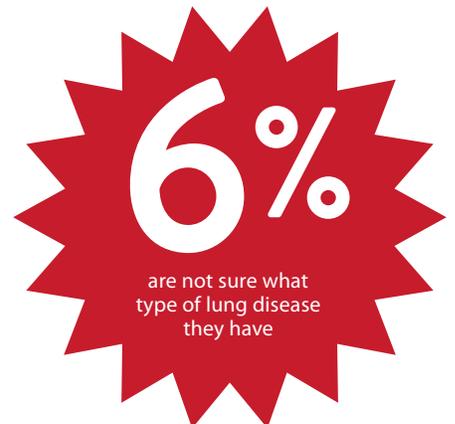
MORE PATIENTS ARE 71-90



MOST HAVE IPF



MOST DID NOT HAVE PRE-EXISTING INFLAMMATORY DISEASE



PATIENTS NEED MORE SUPPORT

“Still waiting to see a Pulmonary Fibrosis doctor to find out what it’s from and how to manage. My lung doctor just said that there’s nothing that could be done”

.....

“My first GP didn’t recognize how ill I was so I changed GP and I was then referred to my now specialist.”

.....

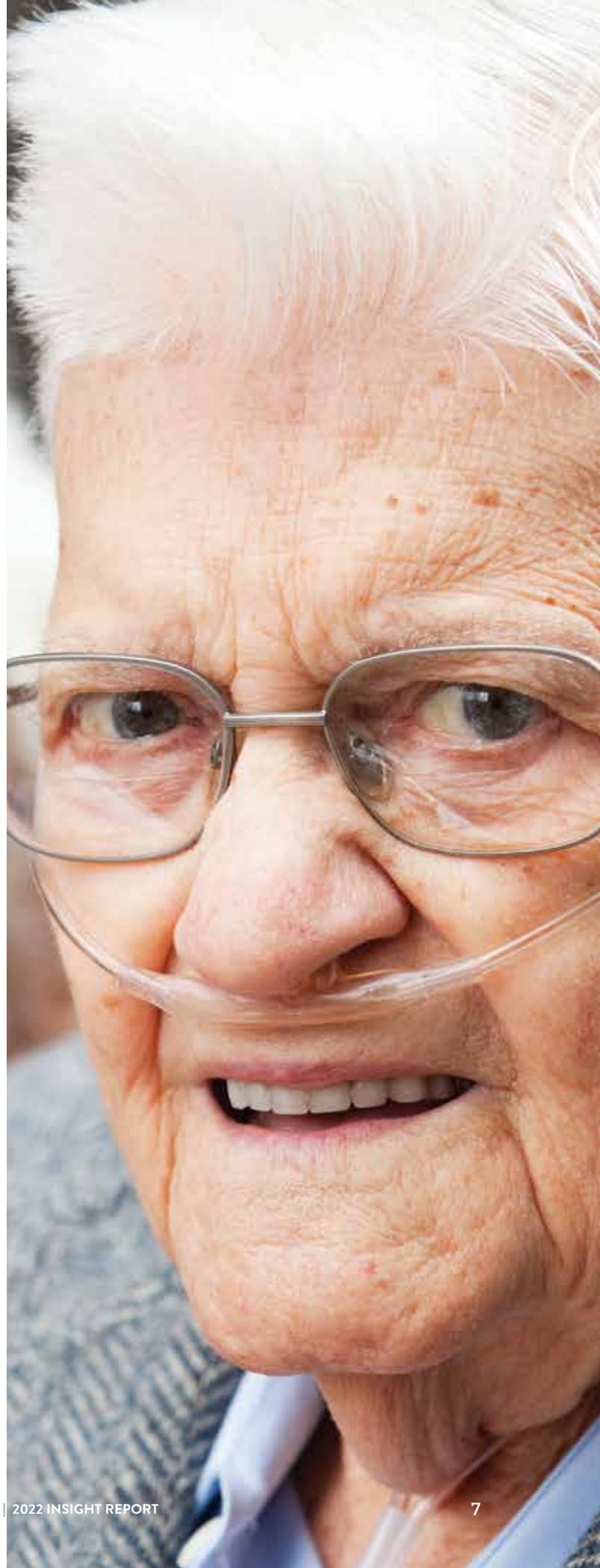
“Have not seen my lung Dr. since being diagnosed. Feels like I’m being discriminated against due to my age.”

.....

“I do not receive treatment or medication.”

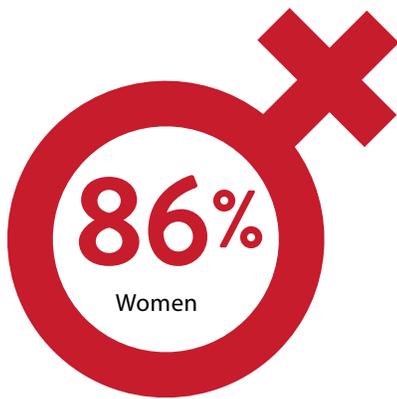
.....

“I feel I’m left on the wayside to struggle on my own.”



THE CAREGIVER

Most are women caring for patients who are older on average than in 2020. More time is spent on caregiving tasks than before.



Percentage of the general population in Canada who identify as indigenous:

5%



1%

Identify as indigenous



INDIGENOUS AND VISIBLE MINORITY CAREGIVERS WERE UNDER-REPRESENTED

Percentage of the general population in Canada who identify as a visible minority:

22%



9%

Identify as a visible minority

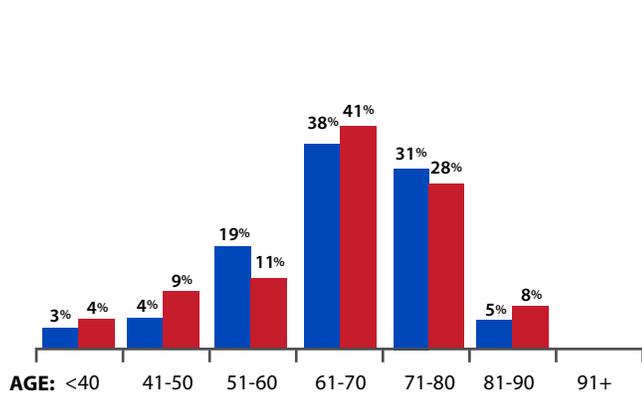
2020

VS

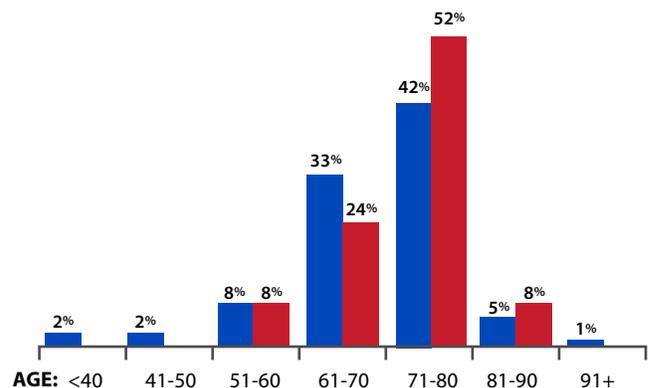
2022



THE NUMBER OF CAREGIVERS AGED 61-70 UP BY 3%



THE AGE OF PATIENT THEY CARE FOR HAS INCREASED: 71-80 (+10%) 81-90 (+4%)



CAREGIVERS NEED CARE

“I feel like I have to find solutions as specialists aren’t providing info, besides medication and waiting to get testing done. Very discouraging.”

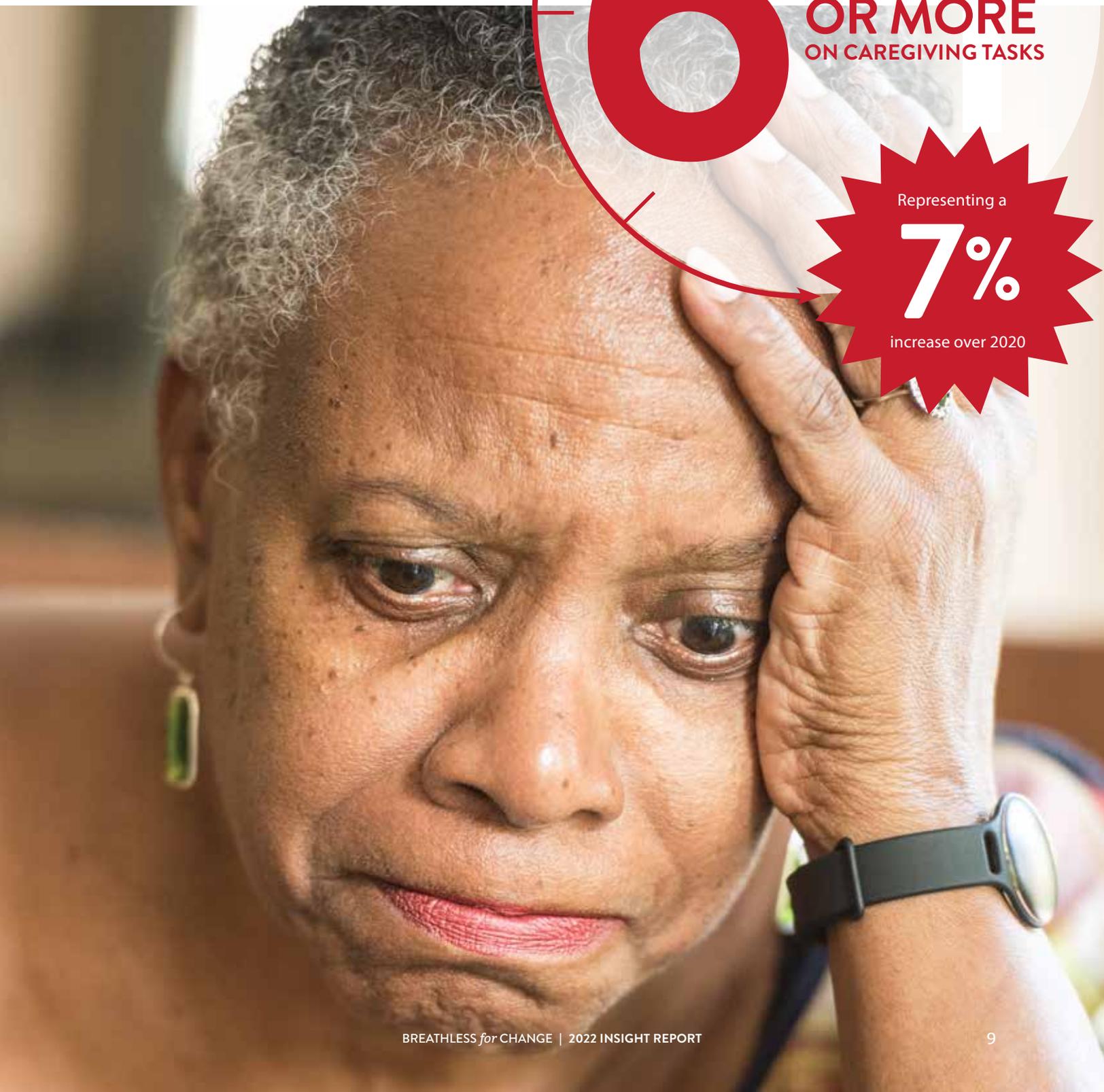
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**18% SPEND
HOURS
PER DAY
OR MORE
ON CAREGIVING TASKS**

Representing a

7%

increase over 2020

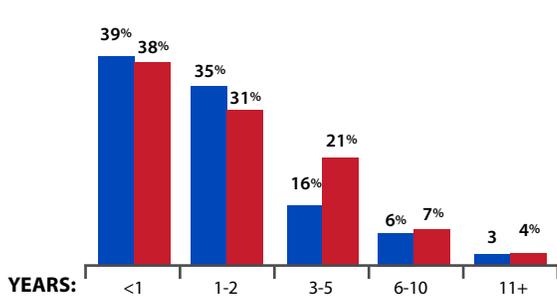


DIAGNOSIS IS STILL LAGGING

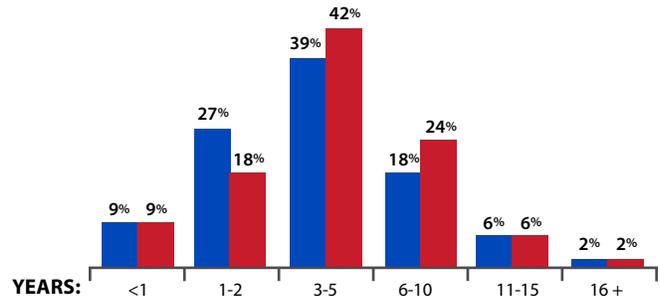
Time from symptom onset to PF diagnosis has grown since 2020. Patients are still more likely to receive a diagnosis from a respirologist than a family doctor.

2020 VS 2022

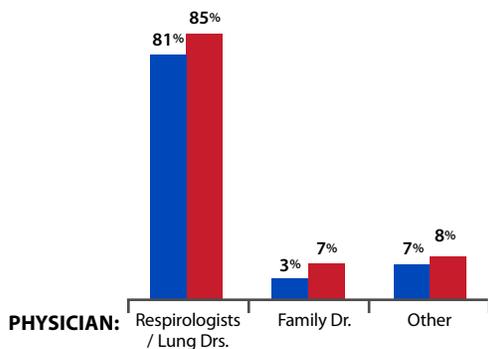
TIME FROM SYMPTOM ONSET TO DIAGNOSIS HAS GROWN



LENGTH OF TIME LIVING WITH PF



RESPIROLOGISTS MORE LIKELY TO DIAGNOSE PF

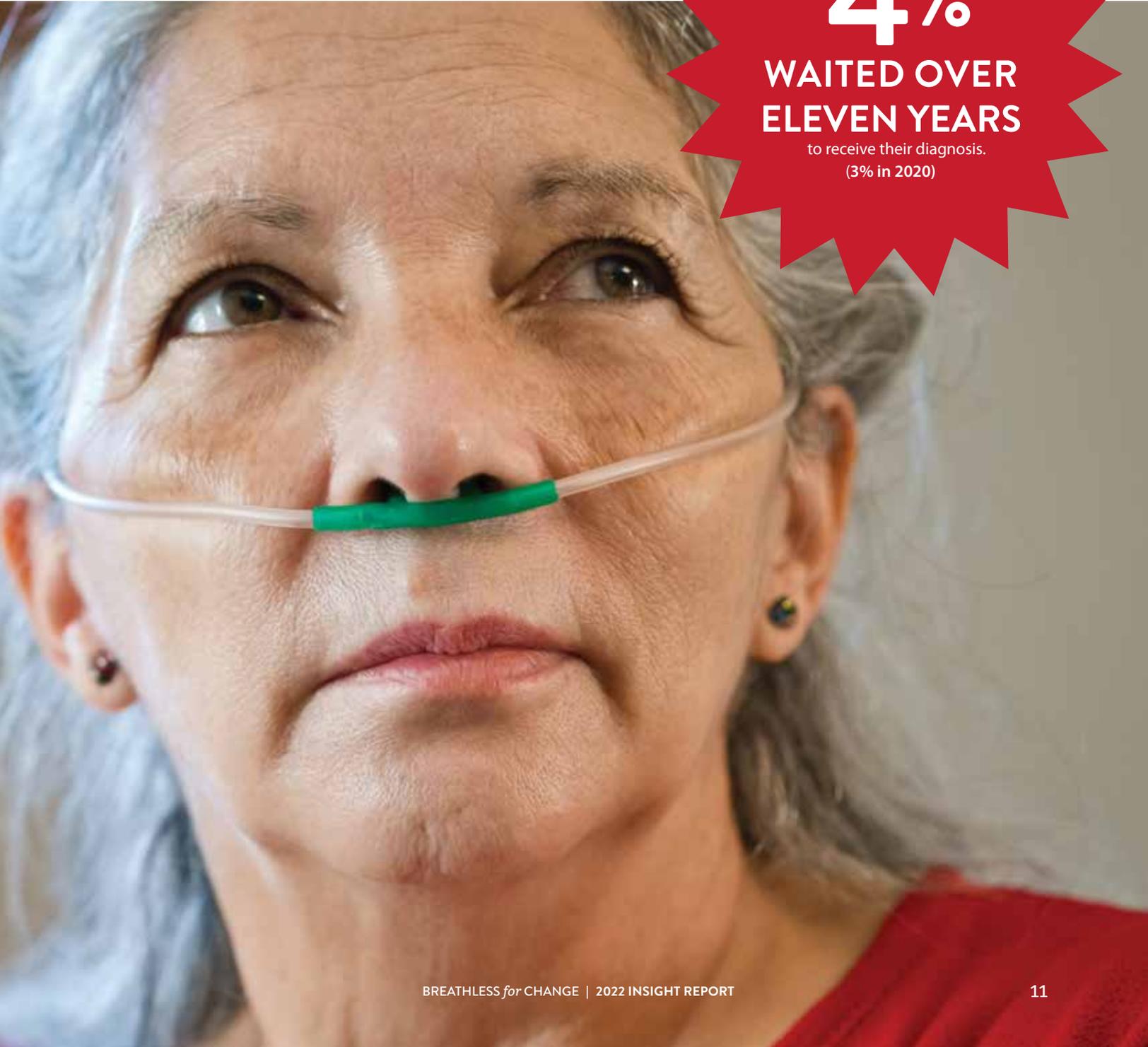




**OVER
3 YRS
WAIT**
for a diagnosis for **ONE
THIRD** of patients



4%
**WAITED OVER
ELEVEN YEARS**
to receive their diagnosis.
(3% in 2020)

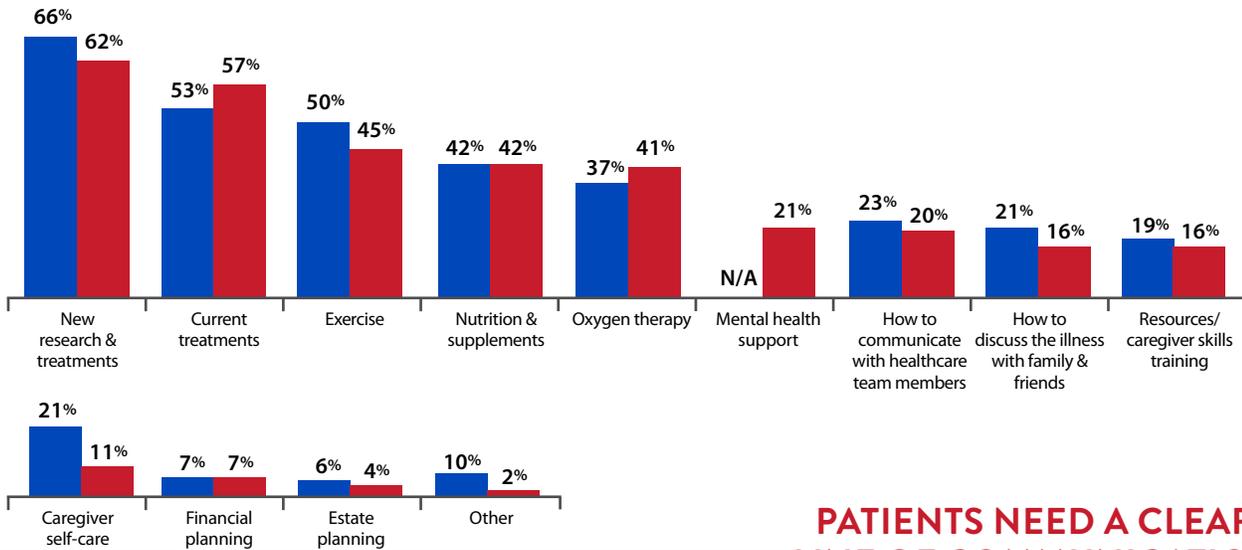


MORE INFO NEEDED

Patients need to know more about research, treatments, support, and exercise. Many cite poor communication from their doctors.

2020 VS 2022

Q: "What types of info would be helpful to you?"

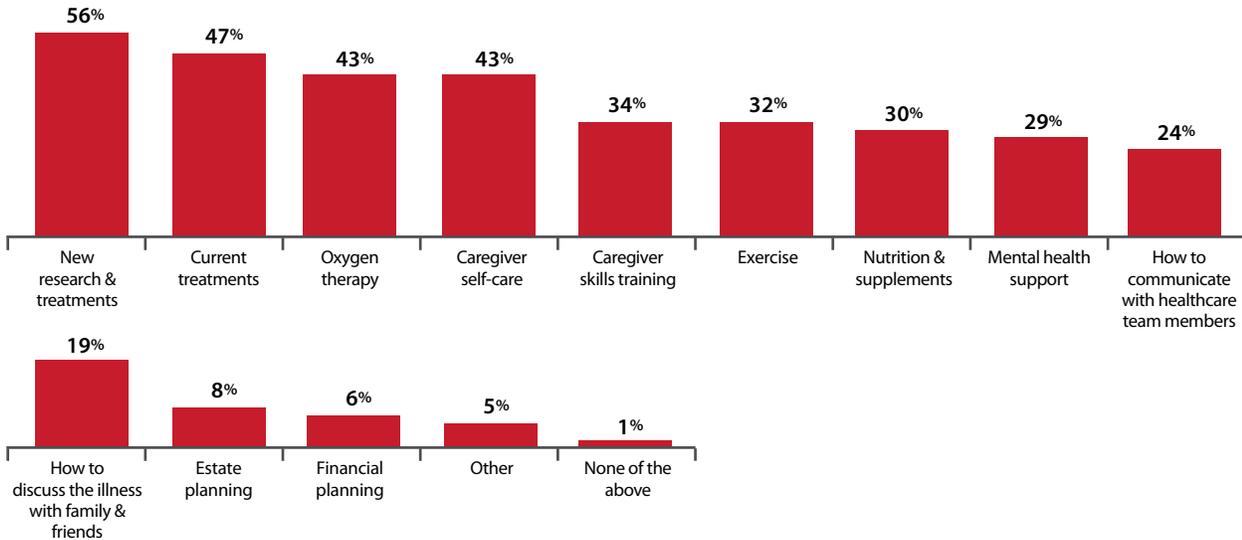


PATIENTS NEED A CLEAR LINE OF COMMUNICATION WITH THEIR DOCTORS

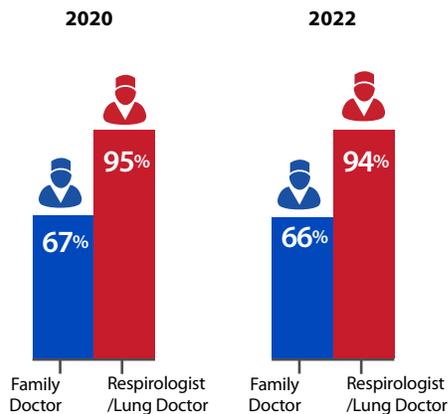
"It's too late for me as my mother is at end stage in hospital but things would have been easier for our family if we understood end stage better and we had some type of support/guidance."



Caregivers want to know what to expect, need mental health and support groups, and more. Some also need info about treatment options and financial assistance.



RESPIROLOGISTS STILL SEEN AS MOST KNOWLEDGABLE

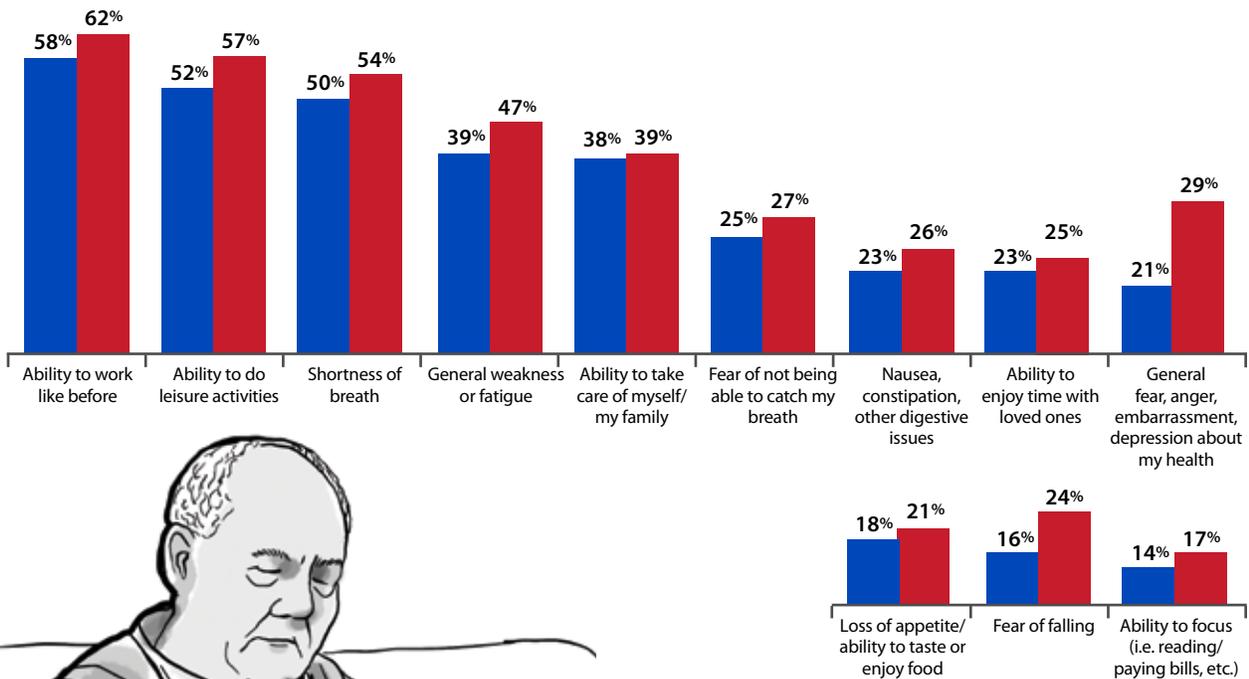


PF'S IMPACT ON THE PATIENT

Conditions have declined since 2020 for people living with PF

2020 VS 2022

Q: "How have each of the following been impacted?"



"Most (of us) are of a generation where there is still a stigma around receiving support for mental/emotional health. I wish we could talk about counselling the way we do about oxygen therapy."

**PATIENTS FEEL TRAPPED
IN THEIR HOMES**

“This is a cruel disease... I loved to go on long walks etc. I was quite active... now I can’t make the bed or vacuum without being out of breath... I can’t go places with my grandkids... I worry about my oxygen when we do go out. We can go for drives and out to eat.”

.....

“I am limited in doing activities outside my home as I am dependent on my oxygen. I have 1 hour a day. If I go food shopping that’s my 1 hour. I also have to rush as I need oxygen to get from my vehicle to my condo.”

.....

“I am not able to do any house or yard work, tired and depressed that I mostly have to stay in my home and am not able to function as I did before this disease”

.....

“The cough and shortness of breath make for social anxiety in mixing with others socially.”

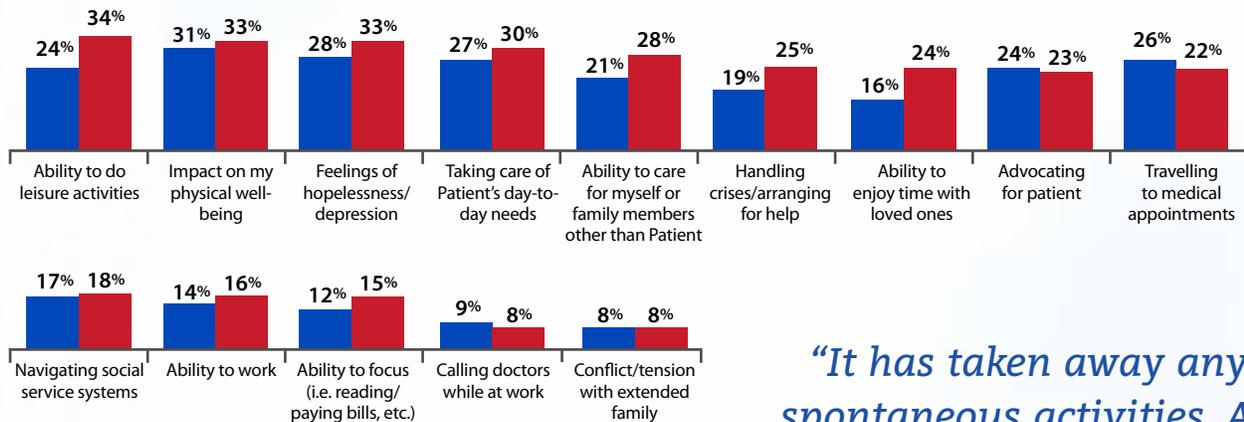


PF'S IMPACT ON THE CAREGIVER

Negative impacts have increased across nearly every metric since 2020.

2020 VS 2022

Q: "How has caregiving impacted your quality of life?"



"It has taken away any spontaneous activities. All need to be planned..."

The number of caregivers who report a negative impact on their ability to enjoy leisure activities:

34%
 VERSES 24%
 IN 2020

Caregivers experiencing feelings of hopelessness and/or depression:

33%
 VERSES 28%
 IN 2020

Q: "How many hours a day do you spend on caregiving tasks?"



CAREGIVERS ARE BURNED OUT

"How to encourage someone who also has depression and anxiety to use what time he has left more meaningfully and less prone to being in their chair or bed."



TREATMENT ACCESS STILL INCONSISTENT

Some patients cannot access needed treatment due to lack of coverage or remote location.

TREATMENT IS INSUFFICIENT

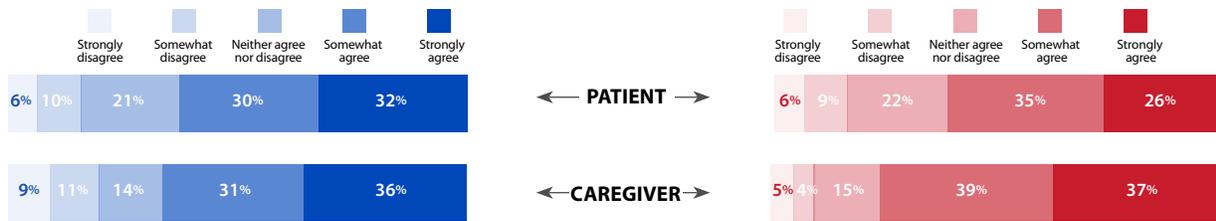
“I am not able to manage my PF. It is worsening and I am in hospital and I want to be put in palliative care.”

“I am in decline and have no idea of ‘what’s next’. Ongoing support is very sketchy. Little or no contact between six-month check-ups.”

TREATMENT NEEDED/ NOT RECEIVING	DUE TO OUT-OF- POCKET COST	DUE TO REMOTE LOCATION
ANTI-FIBROTIC DRUG	6%	8%
PHYSIOTHERAPY	7%	8%
COUNSELLING / EMOTIONAL SUPPORT	10%	11%

While many patients feel that their treatment is effective for managing their PF, a significant number do not.

2020 VS 2022



“Medications did not help except for oxygen.”

“So far there has been no support emotionally. Also, I requested lung physio a year ago”

“I scored low on this because by the time we found out my father had IPF it was too late...”

“Improve government funding for pulmonary fibrosis treatment; I feel it’s left behind in comparison to other serious deadly diseases. It’s a long delay for such a deadly disease, which is a death sentence.”

“Treatment didn’t come soon enough. My husband slipped through the cracks because of COVID...”

“All available treatments have been tried ... the side effects are worse than the disease itself.”

“Side effects are debilitating.”



VISIBLE MINORITY PATIENTS

These patients report a greater need for better access to treatment, especially anti-fibrotic drugs, physiotherapy, and mental health supports.

TREATMENT NEEDED/
NOT RECEIVING

ANTI-FIBROTIC DRUG

PHYSIOTHERAPY

COUNSELLING /
EMOTIONAL SUPPORT

ALL PATIENTS

6%

16%

21%

VS

VISIBLE MINORITY
PATIENTS

18%

26%

31%

Less than

50%

of

VISIBLE MINORITY
PATIENTS

Feel that their current
treatment can manage
their PF

**THESE PATIENTS NEED
EVEN MORE HELP**

“My pulmonologist is quite arrogant as well as his assistant. He never gives me straight answers so I’m asking my physician to refer me to someone else...”

.....

“This is a horrible disease and there needs to be more widespread knowledge... it’s almost like I’m invisible and yet I’m slowly dying.”

.....

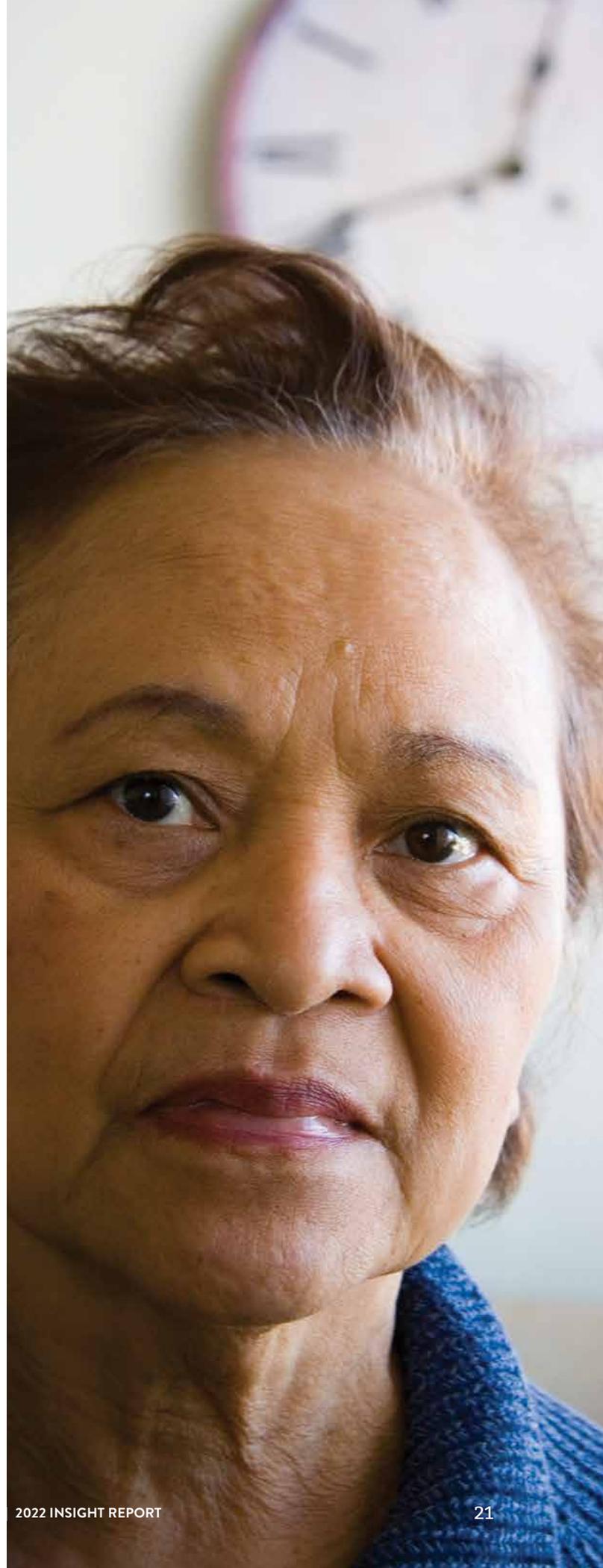
“I would like my specialist to be more forthcoming in discussing my disease. I know I’m dying, but I would like some indication of where I stand... am I doing better, worse or holding my own?...this seems to be the elephant in the room and I think patients are being denied all facts.”

.....

“Never met the lung doctor specialist in person, I was informed by phone.”

.....

“The doctor told me there is no treatment for my diseases.”



OXYGEN IS UNACCEPTABLY SCARCE

For people living with PF, oxygen is essential as soon as they need it. And yet, getting enough oxygen in a timely manner is not assured.

FILLING AN OXYGEN PRESCRIPTION CAN BE A BATTLE

“I had to fight to get oxygen supplies.”

.....

“It took a year for it to go through.”

.....

“I had a hard time getting qualified for oxygen because of improper testing.”

.....

“Dr. said I needed oxygen. Government said no.”



18%

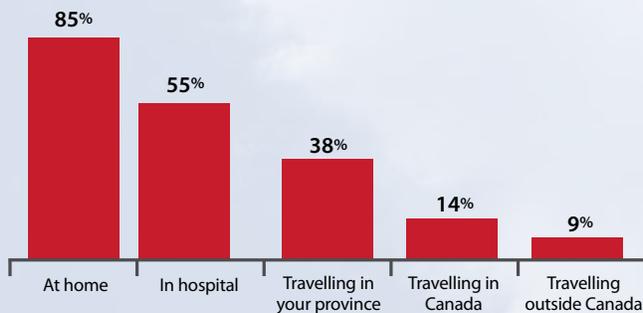
of patients **DID NOT** get an **oxygen therapy prescription** when needed.

3 IN **4**

patients **DID NOT GET NEEDED OXYGEN** the day it was **prescribed.**

50%
WAITED A WEEK OR MORE

ACCESS TO OXYGEN DROPS WHEN TRAVELLING



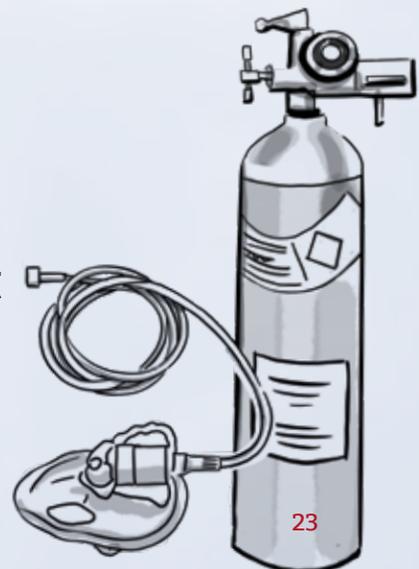
“Oxygen access is ‘good’ to ‘very good’”

“My respirologist wrote me a prescription for oxygen this morning but it is not in place yet.”

“I have tried to advocate for more oxygen cylinders”

OVER **1** IN **3**

have **NO BACKUP OXYGEN** in the event of a **power failure.**



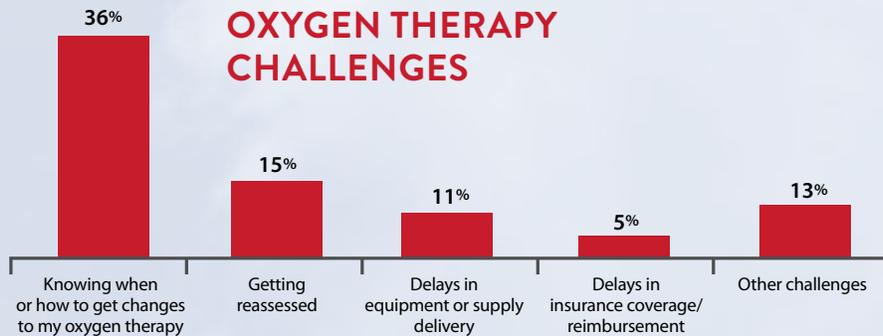


BARRIERS TO OXYGEN THERAPY ARE UNBEARABLE FOR PATIENTS FIGHTING TO BREATHE

**OVER
1 IN
3**

said knowing **HOW TO GET CHANGES** to their oxygen therapy is **their biggest challenge**

“I didn’t get a 6-minute walk test when I complained about being out of breath. I had to bring up the possibility of oxygen.”



Some people are happy with their oxygen therapy access, but for too many, barriers, including financial, persist.

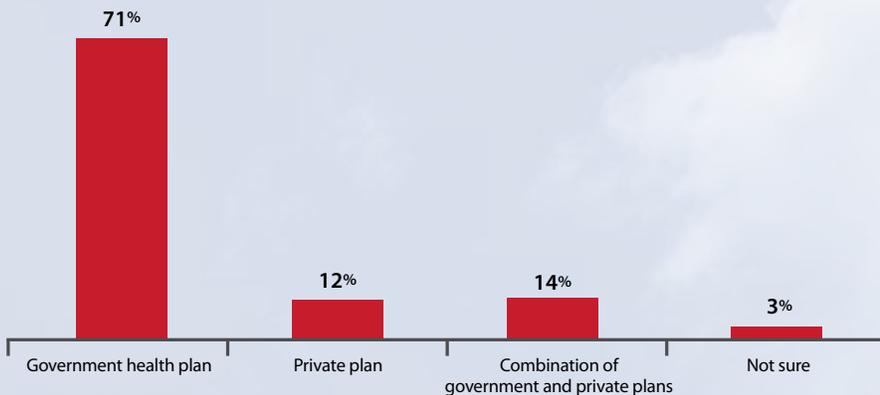
“I had a breathing & walking test at our hospital & received oxygen in a couple of days. They were right on the ball.”

“Local respirologist refused to renew my script. Almost lost coverage. Took over a month to get script renewed.”

“When the lung Dr said I needed O² I got it right away and it has always been covered”



pay
OUT-OF-POCKET



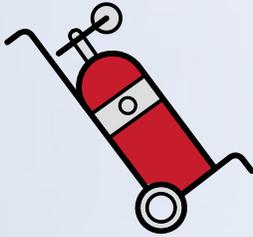
struggle to get
REASSESSED



“I couldn’t do anything, my body was missing oxygen and when you see the doctor they (say to) stay home because it’s not covered... Basically if you’re not dying they don’t give it to you.”

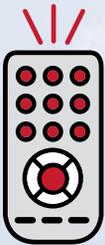
“Be more lenient with access to oxygen therapy... When a patient has a hard time breathing – provide oxygen! Qualification levels should be lowered so people can get the oxygen they need.”

Patients and Caregivers weighed in on what can be done to improve oxygen therapy:



1 Design better cylinders

- Improve unit portability (“Smaller, lighter, easier to move, quieter”).
- Design travel cylinder options (“I cannot fly with a tank”).
- Improve quantity/cylinder for outings (“2 hours isn’t enough”).



2 Enable remote control

- Home system would be better with a remote control.
- Remote monitoring/adjustment of oxygen equipment would help.
- “Design new and different tools for mobility.”



3 Remove barriers to access

- Provide easier access to alternate suppliers.
- Provide a comprehensive listing of provincial/national suppliers.
- Change regulations to allow purchase of portable concentrators.
- “Government must lower the oxygen-level requirements to qualify.”



4 Improve affordability

- Cover more government-funded oxygen so people can get the exercise they need, and not be tethered to a concentrator at home.
- “My coverage for portable tanks is only three tanks per month or six hours out of the home. Any extra I need to pay out of pocket.”



5 Provide support and advocacy

- Provide counselling (“I was not informed that I could increase the oxygen allowed”).
- “When my husband pushed how important my oxygen is for exercise they increased the amount. I worry I will run out.”

CPFF ACTION PLAN

We will...

1

RAMP UP RESOURCES AND SUPPORT

To support the need for vital information at every stage of the PF journey, we will continue to build and aggregate practical PF resources housed in an easy-to-navigate PF virtual library.

We will expand access to support groups for patients and caregivers and make them more accessible by offering virtual meeting options.

2

FIGHT FOR EARLIER DIAGNOSIS & EQUITABLE TREATMENT

To prevent further declines in quality of life, we will continue to lead efforts to shorten diagnosis delays and advocate for more equitable access to treatments (medication, oxygen, mental health, and pulmonary rehabilitation support).

We will also empower those impacted by PF to self-advocate with tools that help influence change.

CPFF's "Four Pillars" are the basis for this Action Plan.

SUPPORT PATIENTS
AND CAREGIVERS



ADVOCACY



AWARENESS



RESEARCH



3

RAISE AWARENESS

We will raise awareness of PF among Canadians to improve empathy for those living with PF, encourage those living with PF to get help earlier, and raise funds to support our cause.

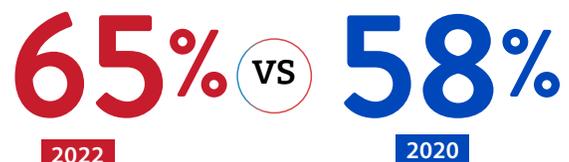
We will increase efforts to reach, understand, and educate visible minority and indigenous populations to better serve them.

4

INVEST IN RESEARCH

We will continue to fund research in Canada in our quest to find a cure for PF and new treatments that improve quality of life for people living with this fatal disease.

AFTER RESPIROLOGIST/LUNG DR,
CAREGIVERS CITE CPFF AS THEIR
MOST IMPORTANT SOURCE OF
INFORMATION



WE ARE BREATHLESS FOR CHANGE



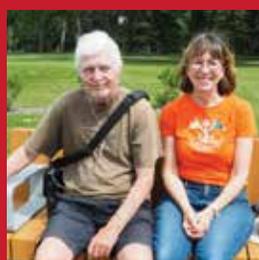
Naomi

Our cover model Naomi Matsushita lives in Toronto with her husband Scott. Naomi works hard on staying fit and sings in a virtual choir for people with lung diseases.



André & Family

André Plouffe lives in Ste. Sophie, Québec with his tight-knit family. André loves the outdoors, is an avid walker, and is happiest fishing at the lake where he can reflect on taking life one step at a time.



Rob & Beth

Rob Garbutt lives with his wife Beth in Winnipeg. Rob received a double lung transplant in 2022 and is fighting with steely determination to return to the many activities he loves.



Jeannie

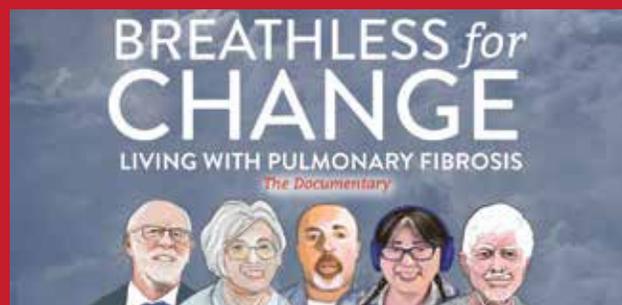
Jeannie Thom is an optimist who surrounds herself with much loved friends in Toronto. Jeannie has for years been a fierce advocate for people living with PF and sclerodoma.



John

When doctors told John Dennis of Halifax he was too old for a lung transplant, he proved them wrong. After recovery, John completed a 300 km bike ride around PEI to raise funds for CPFF.

Learn more about how Naomi, André, Rob, Jeannie and John live with pulmonary fibrosis in CPFF's documentary "Breathless for Change" at cpff.ca



Canadian Pulmonary Fibrosis Foundation

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