

A BREATH OF HOPE

LIVING WITH
PULMONARY FIBROSIS
IN CANADA

2024 PATIENT AND CAREGIVER SURVEY



Canadian
Pulmonary Fibrosis
Foundation

FROM INSIGHT TO ACTION

After completing the 2024 Canada-wide CPFF patient and caregiver survey, we are proud, once again, to share the results with you. As always, we are grateful to all who participated in sharing their experiences with pulmonary fibrosis (PF).

Why is it important to conduct these surveys regularly, you might ask? CPFF prides ourselves on the support we provide to patients, caregivers and everyone affected by pulmonary fibrosis. Having up-to-date information on the experience of living with PF helps us to understand real challenges and to know where we should focus. Since PF is a rare disease, it is not top-of-mind even for many health professionals. We use the information from the survey to educate providers, policy makers and the public about the state of the disease and to keep track of the progress we hope to make.

Patient and caregiver insights gathered over the years have fueled PF research, the creation of much needed support resources, advocacy initiatives, and awareness activities.

In this year's report, we are highlighting how CPFF research, including this survey, informs our actions.

Look for the “From Insight to Action” graphic throughout this publication for a few examples of how important community input is to making real change.



We will never stop fighting for you.
Because... breathing should never be hard work.®



TODD GEORGIEFF
Board Chair

SHARON LEE
Executive Director

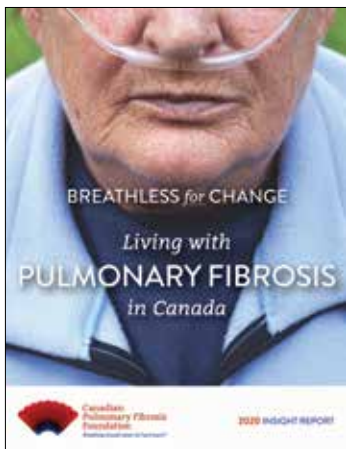
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KNOWLEDGE IS POWER

A famous mathematician said: “You cannot improve what you do not measure”. CPFF’s bi-annual Patient and Caregiver surveys and our 2023 Access to Oxygen reports are making positive change happen.

2020 INSIGHT REPORT



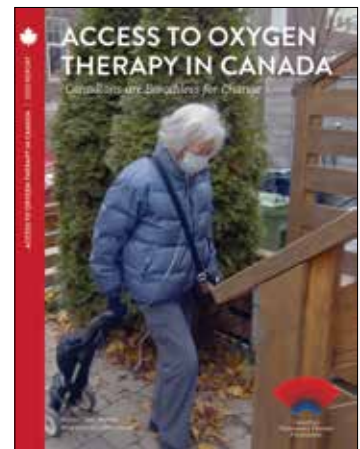
As Canada and the world entered into the unknown of a global pandemic, our spring 2020 survey revealed four significant areas of concern: **diagnosis, information scarcity, inconsistent access to treatment and therapy,** and overall **impact on daily life** for both patients and caregivers.

2022 INSIGHT REPORT



COVID-19 disrupted healthcare systems everywhere, and Canadians living with PF saw their quality of life, treatment and access suffer. **Negative impacts increased across every metric – especially oxygen therapy –** compared to the previous survey. Nearly one in three patients and caregivers felt **fearful, angry, or depressed** – a significant increase compared to 2020.

2023 O2 ACCESS REPORT



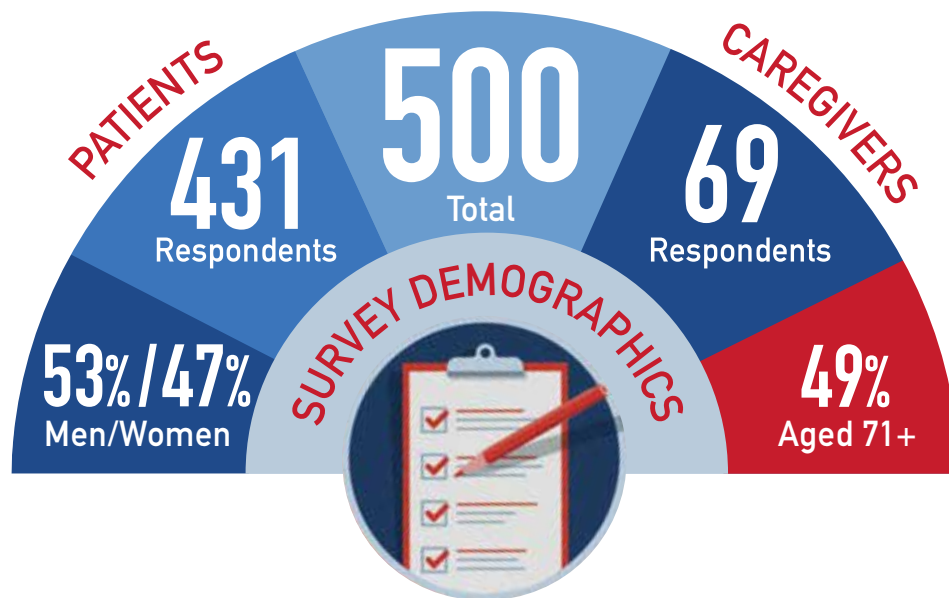
Understanding the challenges for PF patients in accessing supplemental oxygen became a CPFF priority following our report findings. We surveyed patients, healthcare professionals and O2 providers to better understand the patchwork of policies across Canada’s healthcare systems.

They revealed distressing **disparities in medical criteria to qualify, guidelines for PF patients based on COPD patient needs, out-of-pocket expenditures,** and more.

ABOUT THE SURVEY

CPFF asked 500* Canadians about their experiences living with PF. Our goal was to understand how needs are being met and where there are still gaps. Respondents were recruited through CPFF’s database and network (newsletter, social media, medical clinics & associations). Questions covered the following:

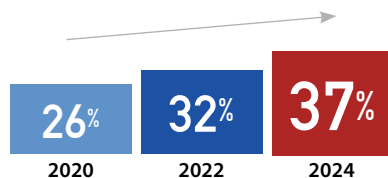
1. Early detection and diagnosis experiences
2. Impact of PF on the lives of patients and caregivers
3. Experiences with available treatments and supplemental oxygen
4. Types of desired support for patients and caregivers
5. Uncovering the needs of under-represented communities and people with pre-existing conditions
6. Changes in diagnosis, treatment access, and quality of life versus previous years



SOME YEAR-OVER-YEAR TRENDS ARE POSITIVE – BUT WE STILL HAVE A LONG WAY TO GO

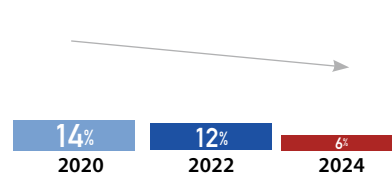
TIME LIVING WITH PF

Time living with PF is **trending upwards** – those living 6+ years show year-over-year increases:



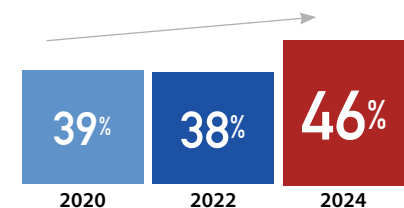
MENTAL HEALTH SUPPORT

Despite rising feelings of hopelessness, **fewer people are receiving** mental health support.



DIAGNOSIS

Number of patients waiting less than a year to receive their PF diagnosis is **trending upwards**:



2 *Note: Respondents answering on behalf of a deceased patient were limited to those who had passed away within the past two years, resulting in a smaller sample size than in previous surveys.

2022 VS 2024

WHAT IS THE SAME?



TOP PHYSICAL SYMPTOMS

Top physical symptoms: **shortness of breath/difficulty catching breath** and general **weakness/feeling tired**.



TOP TREATMENTS

Anti-fibrotic drugs and **oxygen** continue to be the most prevalent treatments received.



TOP DAILY ACTIVITIES IMPACTED

Top patient daily activities impacted: **ability to work, leisure activities**, and ability to **take care of family/self**.



TOP INFORMATION NEEDS

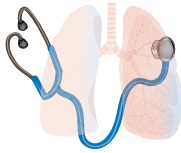
Top information needs remain **research on new treatments** and answers about **current treatments**.



SOURCES OF INFORMATION

Respirologists/lung doctors remain the most important sources of reliable information. **The CPFF website is the most trusted source of info after M.D.s**.

WHAT HAS CHANGED?



DELAYED DIAGNOSIS

The symptoms-to-diagnosis timeline is still slow, but **has shortened** - patients who waited **less than a year** to be diagnosed is up **8 percentage points** from 2022.



CAREGIVER BURNOUT

Caregivers feeling hopeless and/or depressed while taking care of their loved ones day-to-day needs showed an **increase** compared to 2022.



SUPPORT GROUP PARTICIPATION

Participation in support groups **bounced back** from the drop seen in 2022 and **has returned to 2020 levels**.



TIME SPENT CAREGIVING

29% of caregivers spend **6 hours a day or more** on caregiving tasks, a significant increase from **2022 (18%)** and **2020 (11%)**.

KEY HIGHLIGHTS

While many of the same issues as in previous surveys were still prevalent this year, we also delved deeper into the pre-existing condition/PF connection, and the need for more patient education about PF treatments.

DIAGNOSIS STILL SLOW / PRE-EXISTING CONDITIONS COMMON



- Almost **1/3 patients** were diagnosed **with a pre-existing condition** before their PF diagnosis. Gastroesophageal reflux disease (**GERD**) is most prevalent at **17%**.
- Over **50% of patients** waited a year or more to be diagnosed – for over **1/4, 3 yrs+**.
- Most frequent challenges: being **misdiagnosed, lack of access and/or information, and stress**.
- **Over 1/3** of patients have been living with their diagnosis for **6+ years**.

IMPACT ON LIFE IS PROFOUND



- On average, patients report **5 symptoms that have a moderate/large impact**: Top ones are shortness of breath/ inability to catch breath, weakness/tiredness.
- Over **50% of patients** waited a year or more to be diagnosed – for over **1/4, 3 yrs+**.
- Over **1/3 of patients** have been living with their diagnosis for **6+ years**.
- **90% of patients (50% of caregivers) who were working had to stop/cut back**.

TREATMENT SIDE EFFECTS ARE SIGNIFICANT / O2 ACCESS POOR



- About **1/3 patients** do not feel their **current treatment can manage their PF**.
- About **1 in 7 patients** receive **no treatment** and their top reason is because they were **not prescribed**.
- Almost **2/3 patients** on medication say **side effects** (notably gastrointestinal) are **problematic or intolerable** making the case for new treatment options.
- About **1/10 patients** were **unable to receive an oxygen therapy prescription** when needed. **1 in 5 do not have their oxygen costs covered or reimbursed**.

SURVEY SHOWS TREATMENTS ARE SEEN AS INEFFECTIVE



- For the respondents who feel their treatment is ineffective, **over 1/2** feel their /or their loved one's condition is **getting worse**.
- Almost **1 in 3** feel they are **stable but not improving**.

FROM INSIGHT



TO ACTION

CPFF will continue to educate on how the disease and treatments work. Medications can slow progression; they are not a cure. There are lifestyle strategies that can help manage symptoms and side effects.

TAKING A CLOSER LOOK...

Anyone living with, or caring for someone with pulmonary fibrosis in Canada faces challenges: physical, emotional, societal, and systemic. For some sub-groups in our survey, challenges can be exacerbated by where they live or who they are.

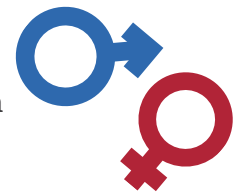
INDIGENOUS / VISIBLE MINORITIES* EXPERIENCE TREATMENT DIFFERENTLY

- The Indigenous community reports **lower usage of anti-inflammatory drugs, physio and mental health counselling** (directionally). This finding requires further investigation.
- About 40% of **visible minority patients** feel their current treatment/routine can manage their PF. (vs. 30%)



MALE / FEMALE PATIENTS HAVE DIFFERING EXPERIENCES

- IPF shows higher prevalence among men (85% vs. 69%)
- Men show shorter interval from symptoms to diagnosis than women – specifically when looking at being diagnosed in under 2 years (77% vs. 69%).
- More women patients do not feel their current treatment/routine can help them manage their PF compared to men (41% vs. 33%).



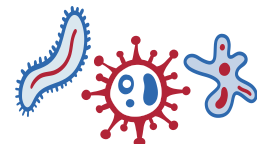
UNDERSERVED RURAL COMMUNITIES*

- Directionally, those who live in more rural areas show a **longer interval between symptoms to diagnosis**.



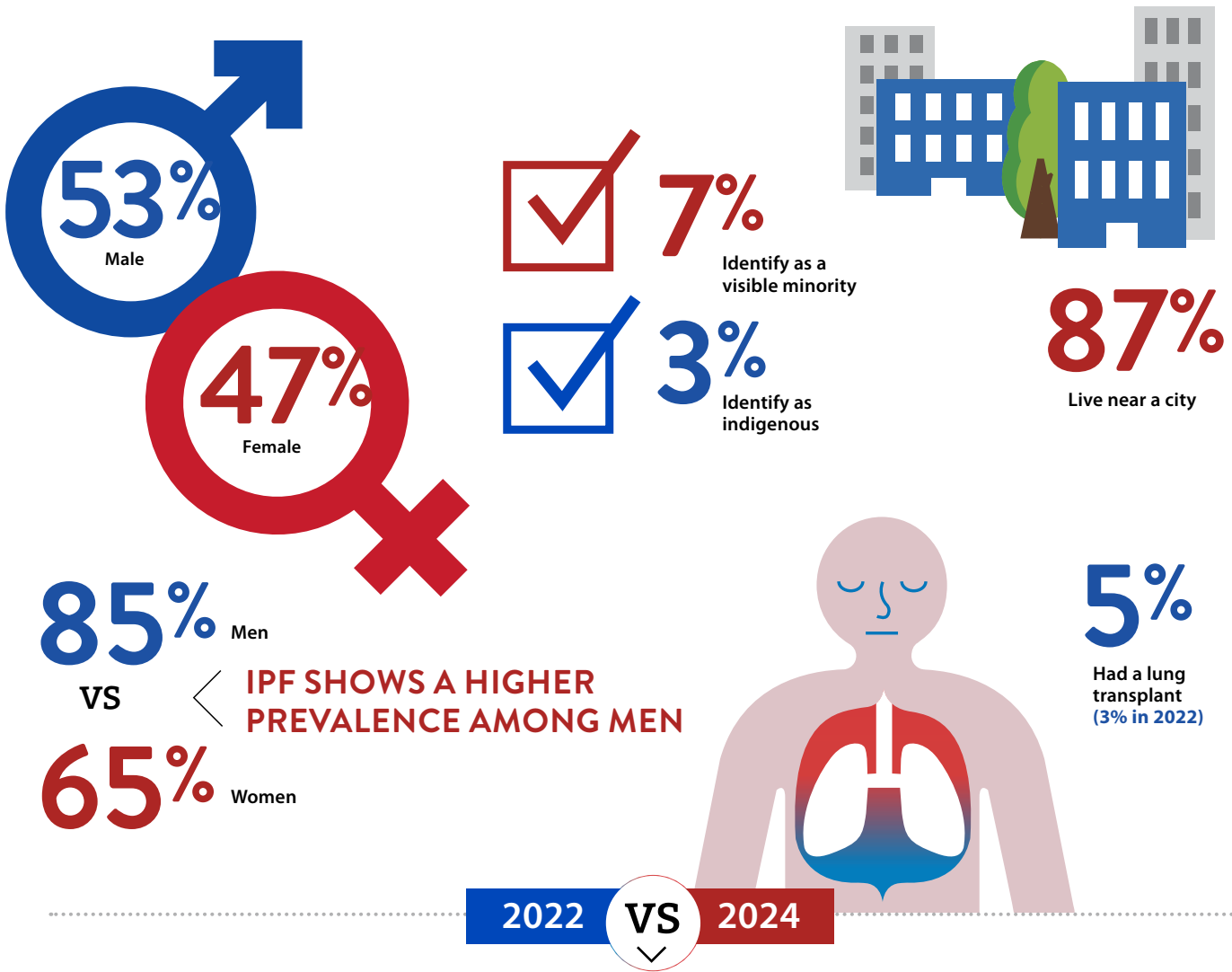
PRE-EXISTING CONDITIONS CAN BE RED FLAGS FOR PF

- Women have more pre-existing conditions (38% vs. 25%) – specifically GERD, chronic autoimmune inflammatory diseases such as rheumatoid arthritis, and scleroderma.
- Patients with pre-existing conditions report **longer time from symptoms to diagnosis**.

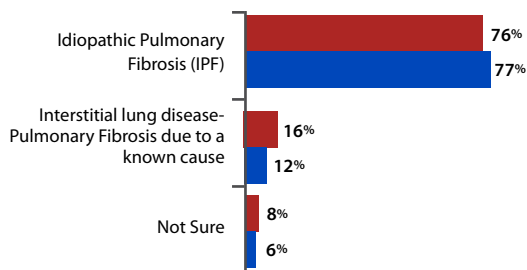


THE PATIENT

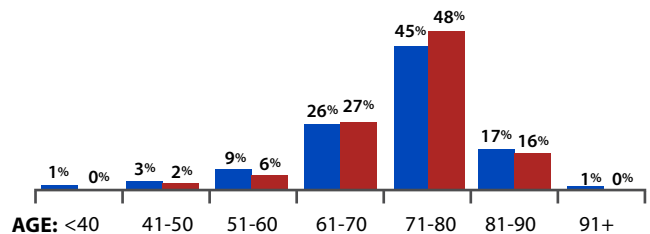
According to our survey, the typical patient is older and lives near a city. Approximately one in three have a pre-existing condition.



MOST HAVE IPF/ILD FROM A KNOWN CAUSE HAS INCREASED SINCE 2022.



MOST PATIENTS ARE OVER 60. ALMOST TWO-THIRDS ARE 71+.





31% HAVE A PRE-EXISTING CONDITION

"I first went in to see my respirologist for a chronic cough that I've had for more than 10 years. First appointment was 2015. Treated for possible GERD... After bilateral knee surgery, Apr 2022, I came out with very low O2 levels. Returned to the respirologist June 22 and was diagnosed with IPF."

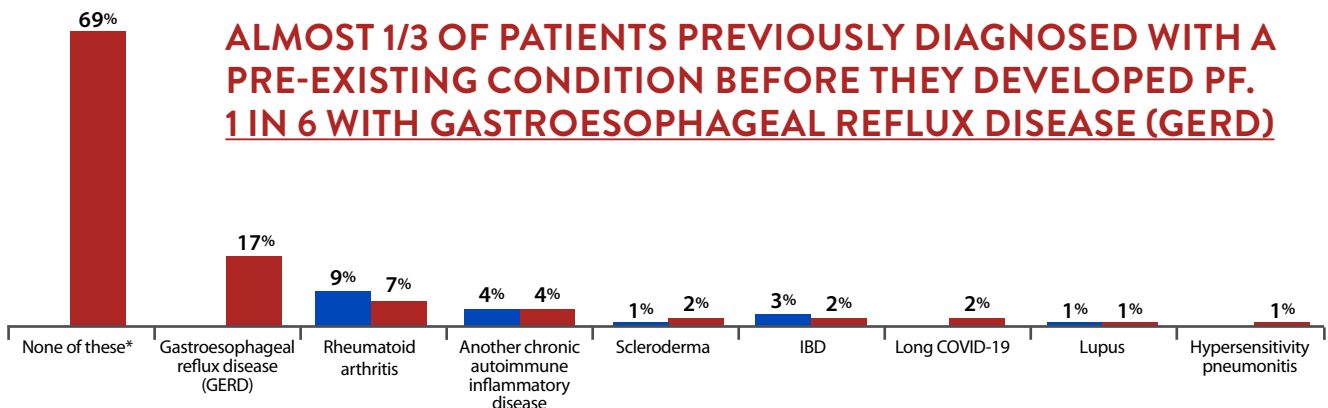
PATIENT

MORE WOMEN THAN MEN HAVE A PRE-EXISTING CONDITION:

38% vs **25%**
Women Men

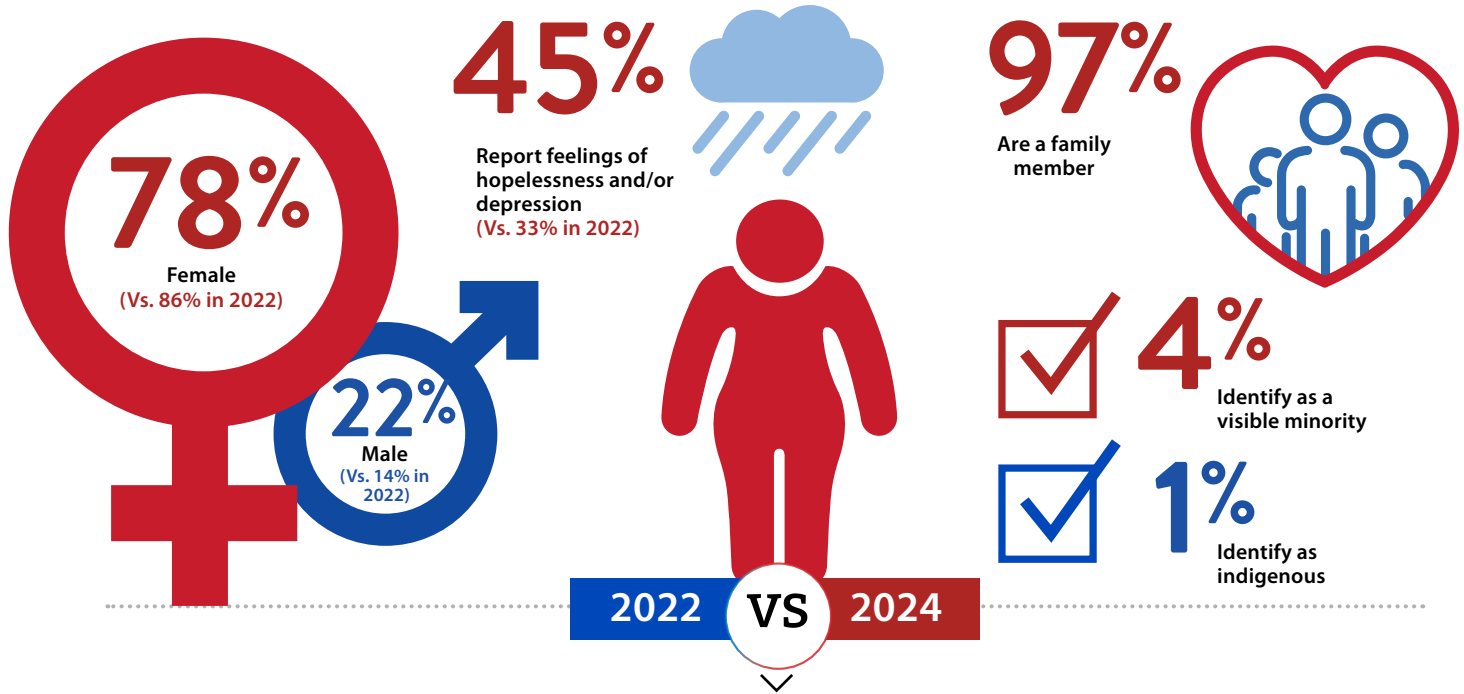
GERD
19% vs **14%**
Women Men

Rheumatoid arthritis
9% vs **5%**
Women Men

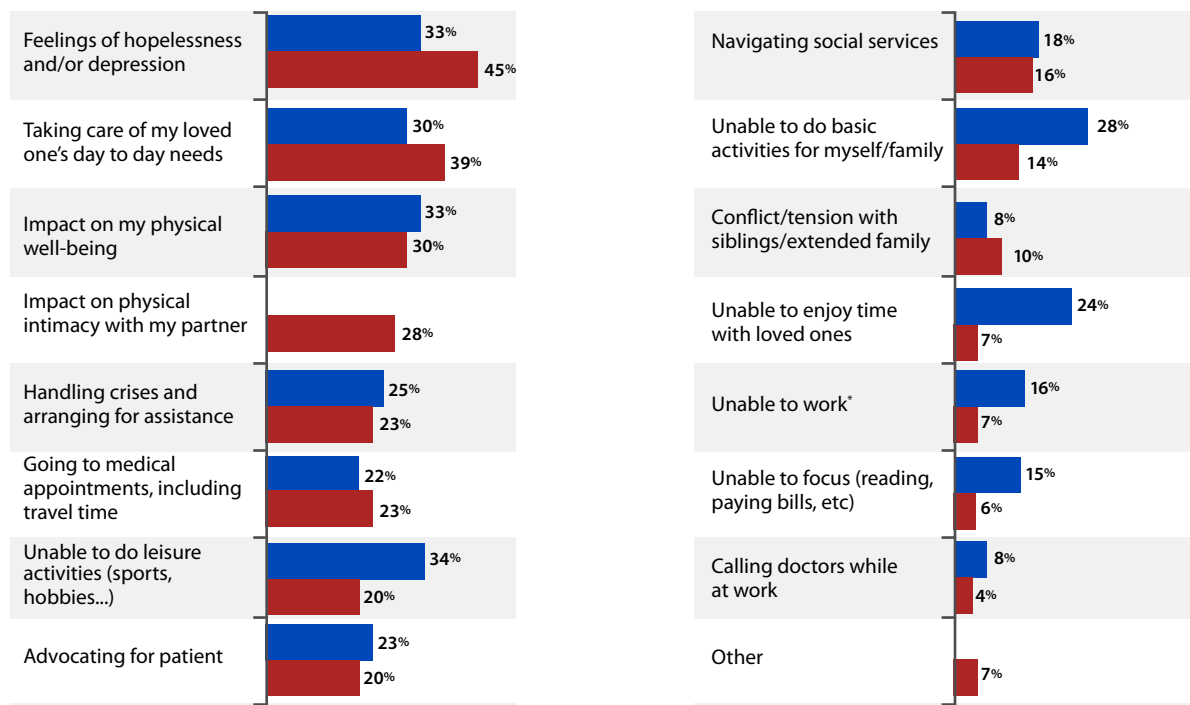


THE CAREGIVER

The typical caregiver is a female family member who is more depressed than in 2022.



BEING A CAREGIVER IS HARD. IT TAKES A PHYSICAL AND EMOTIONAL TOLL. WE ASKED CAREGIVERS TO RANK IMPACTS ON THEIR QUALITY OF LIFE.



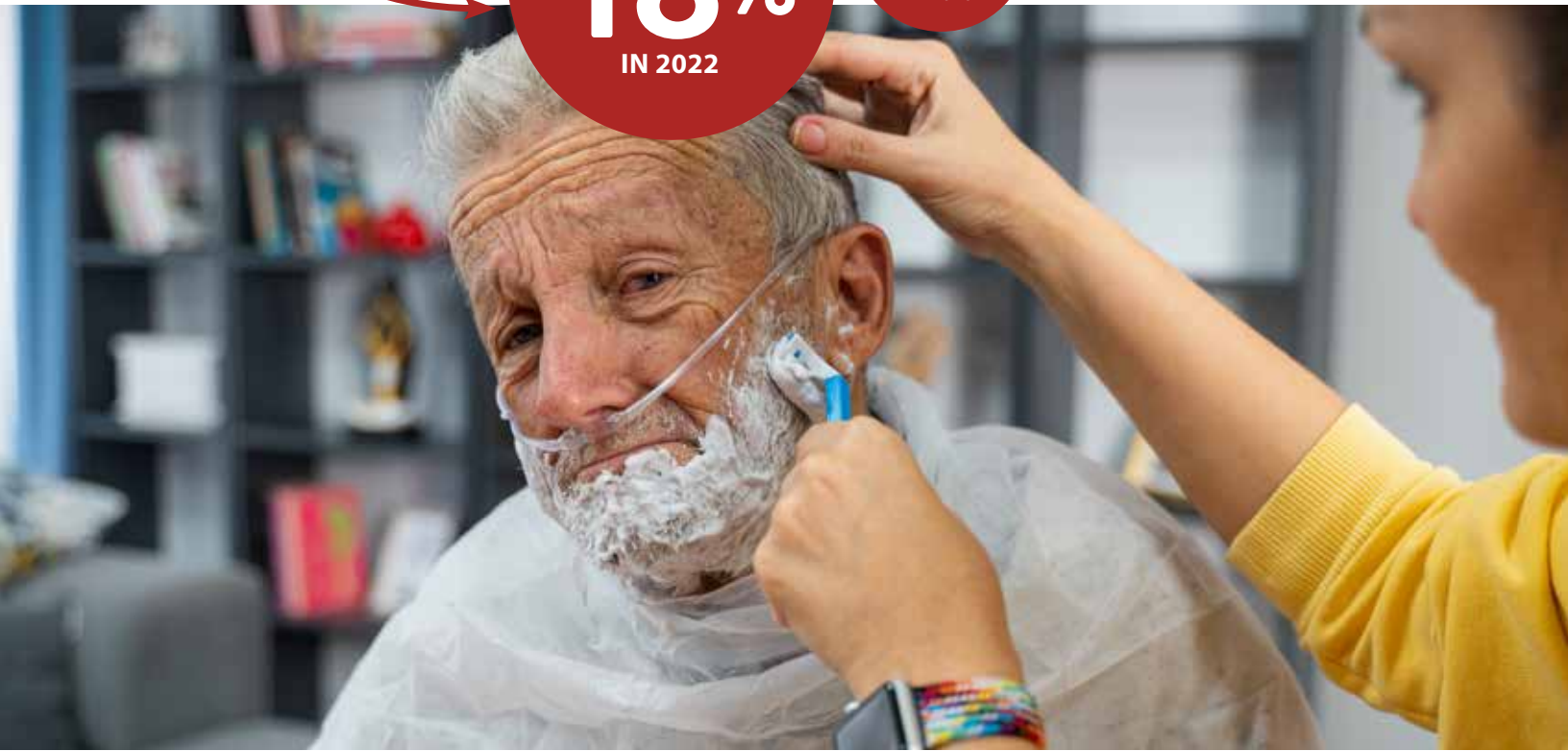


29%

SPEND 6 HOURS PER DAY OR MORE ON CAREGIVING TASKS

COMPARED TO
18%
IN 2022

... AND
11%
IN 2020



JUST OVER HALF OF CAREGIVERS SAID IT HAS IMPACTED THEIR EMPLOYMENT*:

25%

Has had to fully stop working

29%

Have had to reduce working hours

*Due to sample sizes of these groups, results are directional. Excludes respondents who weren't working

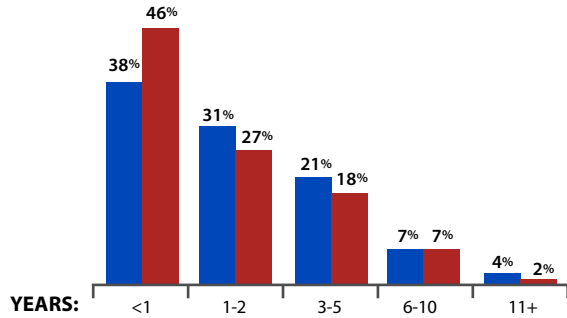
DIAGNOSIS

Patients are receiving their PF diagnosis faster than before, but many are still facing lengthy challenges in getting their diagnosis.

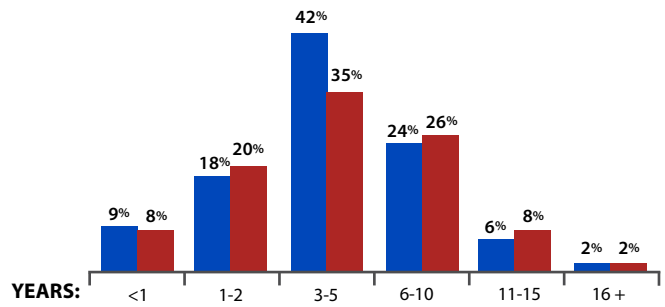
2022 VS 2024

PATIENTS WHO WERE DIAGNOSED IN LESS THAN A YEAR UP 21% VS 2022

Q: How long after your lung problems began were you diagnosed with PF/ILD?

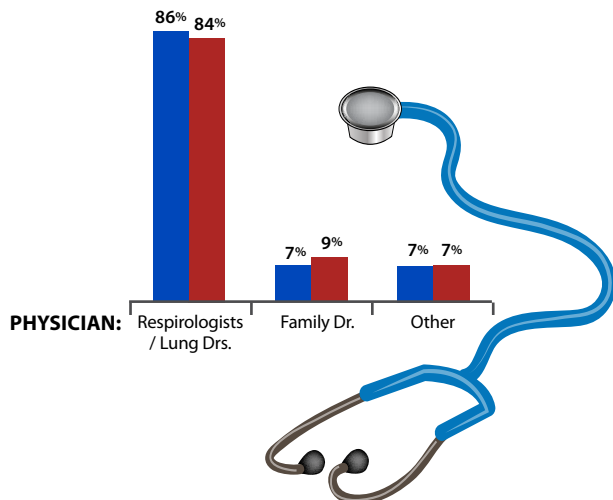


36% OF PATIENTS ARE LIVING WITH PF MORE THAN 5 YRS AFTER DIAGNOSIS



“No doctor could find out what was wrong. I had 4 different doctors including a well-known respirologist, many tests including a bronchoscopy, CT scans, X-rays... It took four doctors six years to figure it out.” **PATIENT**

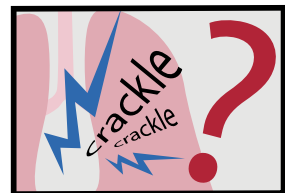
MORE NON-RESPIROLOGISTS ARE DIAGNOSING PF



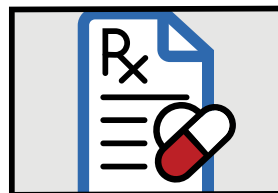
MOST FREQUENT DIAGNOSIS CHALLENGES REPORTED:



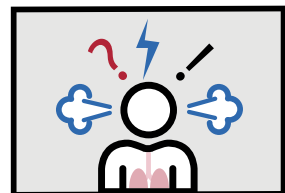
Lack of access/slow



Lack of knowledge by healthcare professionals



Misdiagnosis



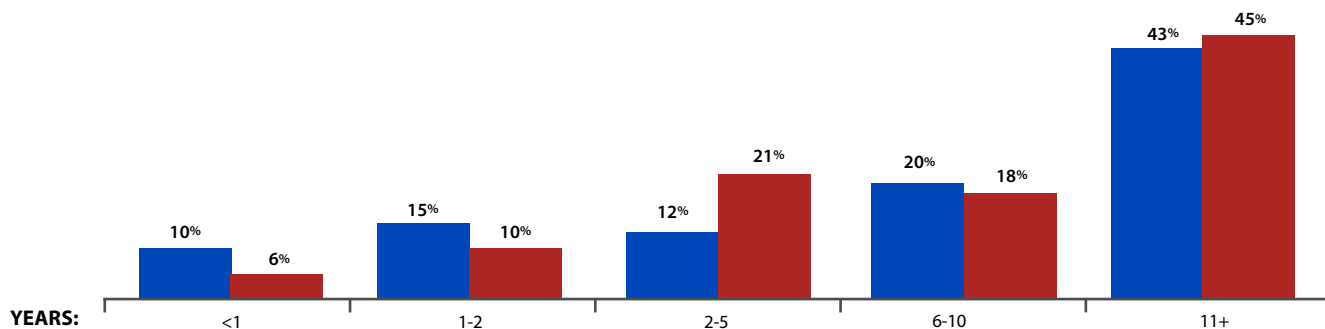
Stress, fear, lack of emotional support

A PRE-EXISTING “BLINDSPOT”

Certain pre-existing conditions should flag patients for possible risk of PF. Yet, people with these conditions tend to receive a delayed PF diagnosis.

2022 VS 2024

ALMOST 2/3 OF PATIENTS HAD PRE-EXISTING CONDITIONS FOR 6 OR MORE YEARS BEFORE EXPERIENCING SERIOUS LUNG OR BREATHING PROBLEMS.



MEN, PEOPLE WHO LIVE IN URBAN AREAS, THOSE WITHOUT PRE-EXISTING CONDITIONS SHOW A SHORTER TIME FROM SYMPTOMS TO DIAGNOSIS.

| | Total | Gender | | Residence | | Pre-existing conditions | |
|---------------|-------|--------|-------|-----------|-------|-------------------------|-----|
| | | Men | Women | Urban | Rural | Yes | No |
| Sample size | 500 | 266 | 233 | 438 | 62 | 155 | 345 |
| < 1 year | 46% | 47% | 45% | 47% | 37% | 37% | 50% |
| 1 to 2 years | 27% | 30% | 24% | 27% | 29% | 30% | 26% |
| 3-5 years | 18% | 16% | 19% | 18% | 16% | 20% | 17% |
| 6 to 10 years | 7% | 5% | 9% | 6% | 11% | 8% | 6% |
| 11 years + | 2% | 2% | 3% | 2% | 6% | 5% | 1% |

FROM INSIGHT



TO ACTION

CPFF's "Tackle the Crackle" educational campaign is raising awareness among the public and medical professionals. The campaign demonstrates how to recognize the signs of PF, specifically by listening for tell-tale crackles associated with lung fibrosis, including for patients with pre-existing conditions.

LISTEN
FOR THE SIGNS OF PF



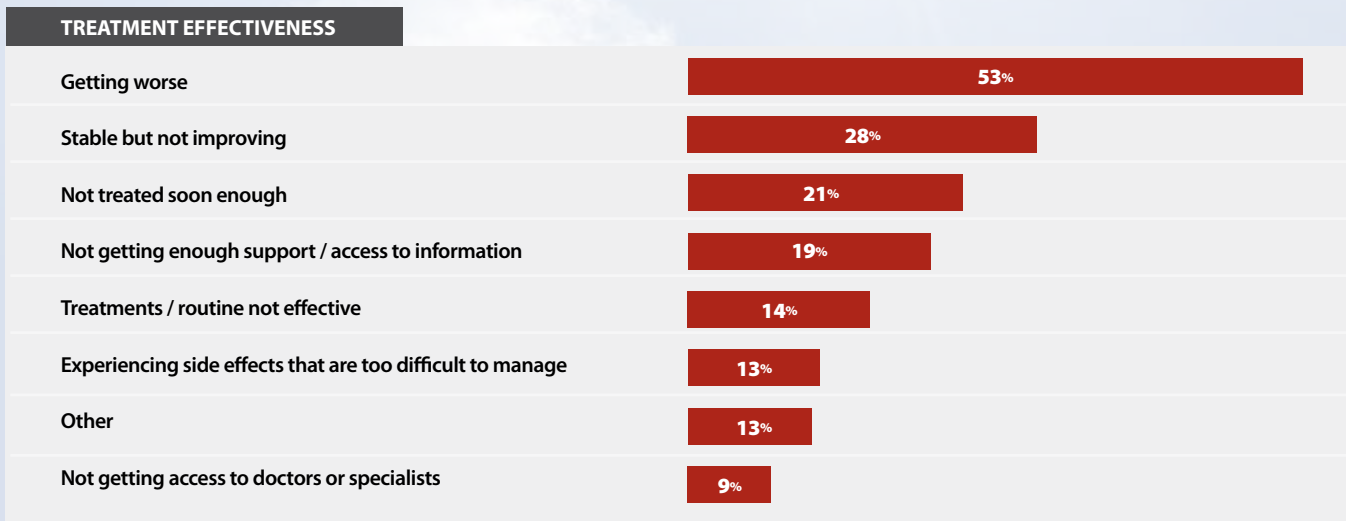
ASK YOUR DR TO
**TACKLE THE
CRACKLE**



TREATMENT

Patient's conditions are worsening, feel they are not treated soon enough, and do not think they can manage their PF with their current treatment/routine.

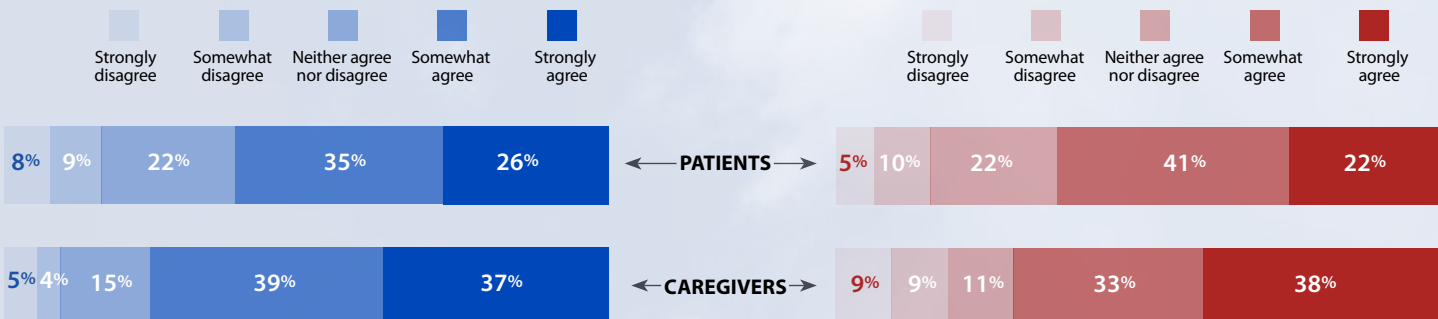
OVER HALF OF RESPONDENTS FEEL THE PATIENT IS GETTING WORSE. ALMOST 1 IN 3 FEEL THEY ARE STABLE BUT NOT IMPROVING. 1/5 SAID THEY WERE NOT TREATED SOON ENOUGH.



ABOUT 1 IN 3 PATIENTS AND CAREGIVERS DO NOT FEEL THEIR CURRENT TREATMENT/ROUTINE CAN HELP THEM/THEIR LOVED ONE MANAGE THEIR PULMONARY FIBROSIS.



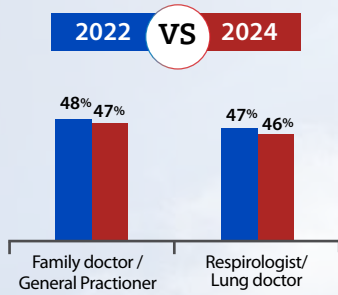
Q: Please rate how much you agree or disagree with this statement:
 "The treatments or routine I am currently receiving are able to manage my pulmonary fibrosis"



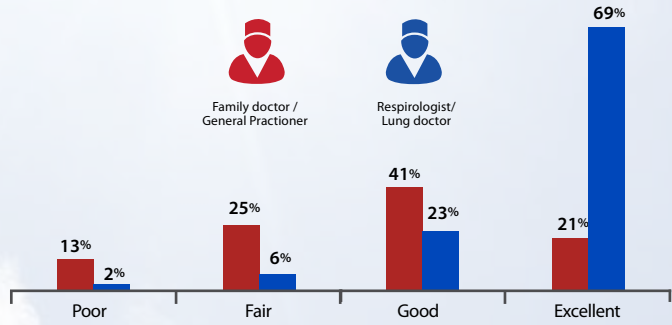
DOCTOR EXPERIENCE

RESPIROLOGISTS/LUNG DOCTORS ARE STILL REGARDED AS MORE KNOWLEDGEABLE THAN FAMILY DOCTORS / GENERAL PRACTITIONERS

Q: What type of doctor do you see for most of your care?

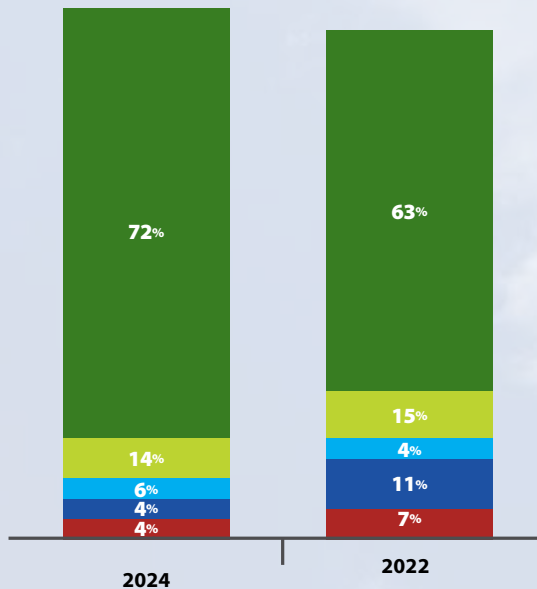


Q: How would you rate their knowledge about pulmonary fibrosis?



OXYGEN THERAPY

ACCESS TO OXYGEN PRESCRIPTION HAS IMPROVED SINCE 2022, HOWEVER MANY PATIENTS COULD NOT GET A PRESCRIPTION WHEN NEEDED.



"It was difficult to access a supplementary oxygen supply. It was as if the application was for a poison..."

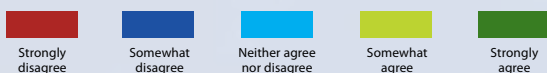
PATIENT



MORE PATIENTS ARE PAYING OUT OF POCKET FOR A PORTION OF THEIR O2

15% vs 19%
2022 vs 2024

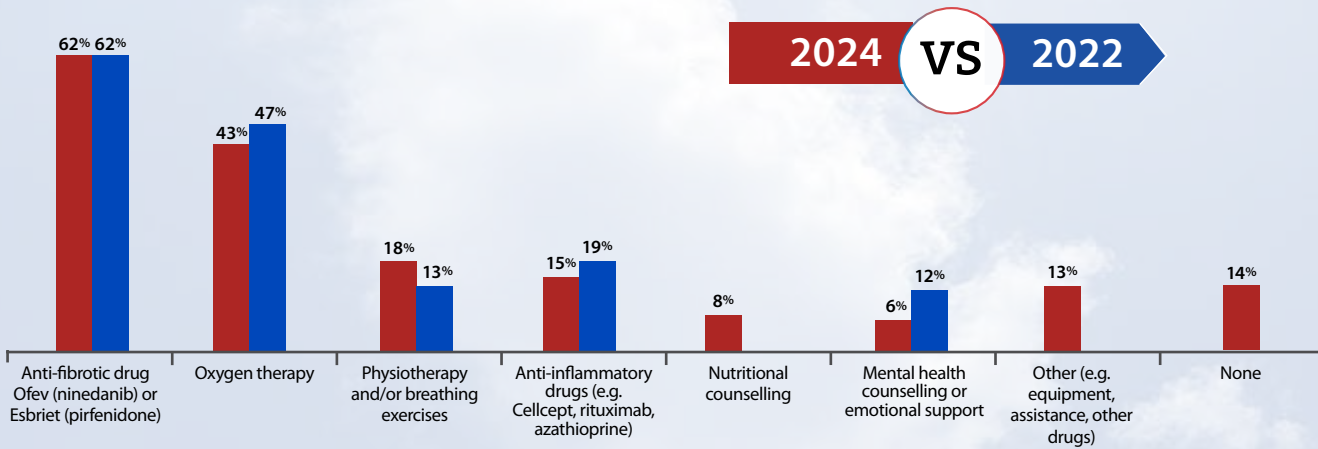
Q: How much you agree or disagree with this statement: "I received an oxygen prescription when I needed it".



TREATMENT

TREATMENTS RECEIVED

ANTI-FIBROTICS NINTEDANIB AND PIRFENIDONE STILL MOST PREVALENT TREATMENTS, FOLLOWED BY OXYGEN THERAPY AND ANTI-INFLAMMATORY DRUGS. MENTAL HEALTH COUNSELLING/EMOTIONAL SUPPORT CONTINUE TO SHOW DECLINE.



Difficulty accessing treatment is still affecting many patients.

REASONS FOR TREATMENTS NOT RECEIVED

REASONS FOR NOT RECEIVING TREATMENT (MEN AND WOMEN)

58%

Not prescribed

1%

No health plan / coverage

3%

Not available in my area

11%

Not interested

37%

Other

"Waiting... (delivery/arrival/approval)"
 "Still being tested/evaluated"
 "Not needed yet"
 "Joining drug trial"
 "Post transplant"
 "Was denied"
 "Side effects"

ALMOST 2/3 SAY SIDE EFFECTS – MOST COMMONLY GASTROINTESTINAL AND FATIGUE – ARE “PROBLEMATIC OR INTOLERABLE”.


| | |
|---------------------------------------|-----|
| Gastrointestinal | 44% |
| Fatigue | 41% |
| Loss of appetite | 32% |
| Nausea | 25% |
| Weight loss | 23% |
| Dizziness | 20% |
| Headaches | 13% |
| Pressure or tenderness in the sinuses | 11% |
| Stomach pain | 10% |
| Heartburn | 9% |
| Vomiting | 9% |
| Other | 5% |

“After my severe cough subsided, my greatest challenge for many years was dealing with severe side effects of OFEV.”

PATIENT


Medication side-effects can be debilitating – but new drugs are on the way.

FROM INSIGHT




TO ACTION

CPFF SHARES PATIENT FEEDBACK WITH THE MEDICAL RESEARCH COMMUNITY




CPFF’s Patient and Caregiver surveys provide invaluable real-world feedback to medical researchers. After a decade without new treatments, we are pleased to report that there are **new drugs in the pipeline** to help patients better manage and treat their PF, giving hope to patients and caregivers for a better future.




Reducing chronic cough associated with IPF

New drugs are aimed at:



Reducing fibrosis and inflammation



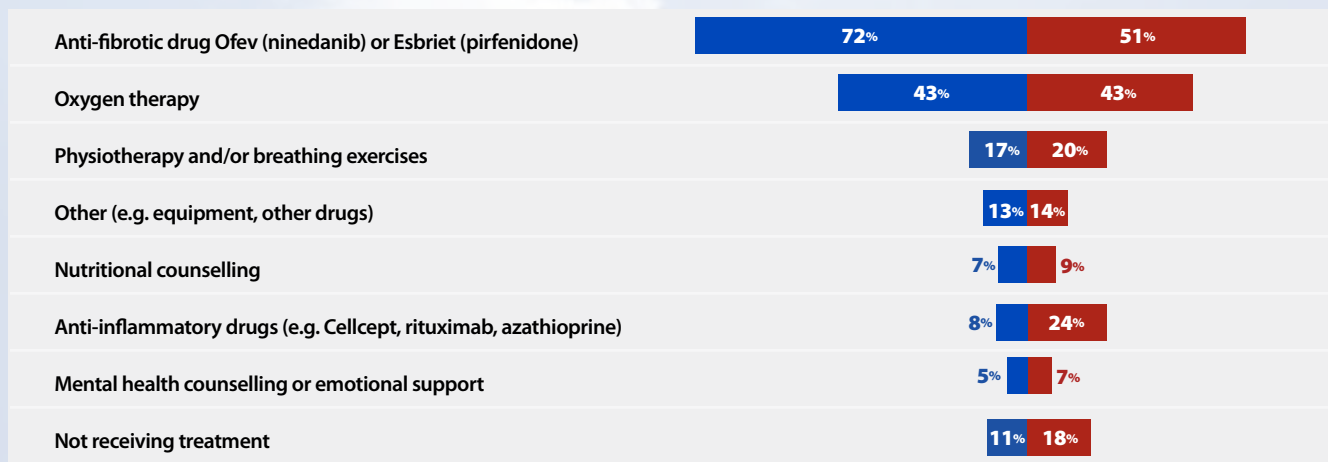
Slowing down or halting IPF progression

TREATMENT

The survey revealed significant differences in how women and men experience their pulmonary fibrosis treatment.

MEN VS WOMEN

MEN ARE MORE LIKELY TO BE RECEIVING ANTI-FIBROTIC DRUGS, WOMEN TAKE MORE ANTI-INFLAMMATORY DRUGS OR DO NOT RECEIVE TREATMENT.



WOMEN FEEL THEY ARE LESS ABLE TO MANAGE THEIR PF WITH THEIR CURRENT TREATMENT / ROUTINE.

“I have had issues several times where I had to end up at the ER but my specialist never calls me back when I call her office... I find it extremely difficult to move around and have severe vertigo. My heart condition is not so bad but the IPF is killing me and I get no support from my medical team.”

PATIENT



Q: Do you agree or disagree with the following statement: “The treatments or routine I am currently receiving are able to manage my PF.”

AGREE

67% VS 59%

DISAGREE

37% VS 41%



“It all started with shortness of breath which led to stents with no results then a triple bypass which didn’t seem to help. After the heart stuff didn’t really show any improvement doctors continued to look for a cause and decided it was a lung issue and things went forward from there. Turns out I had fibrosis caused by RA.”

PATIENT

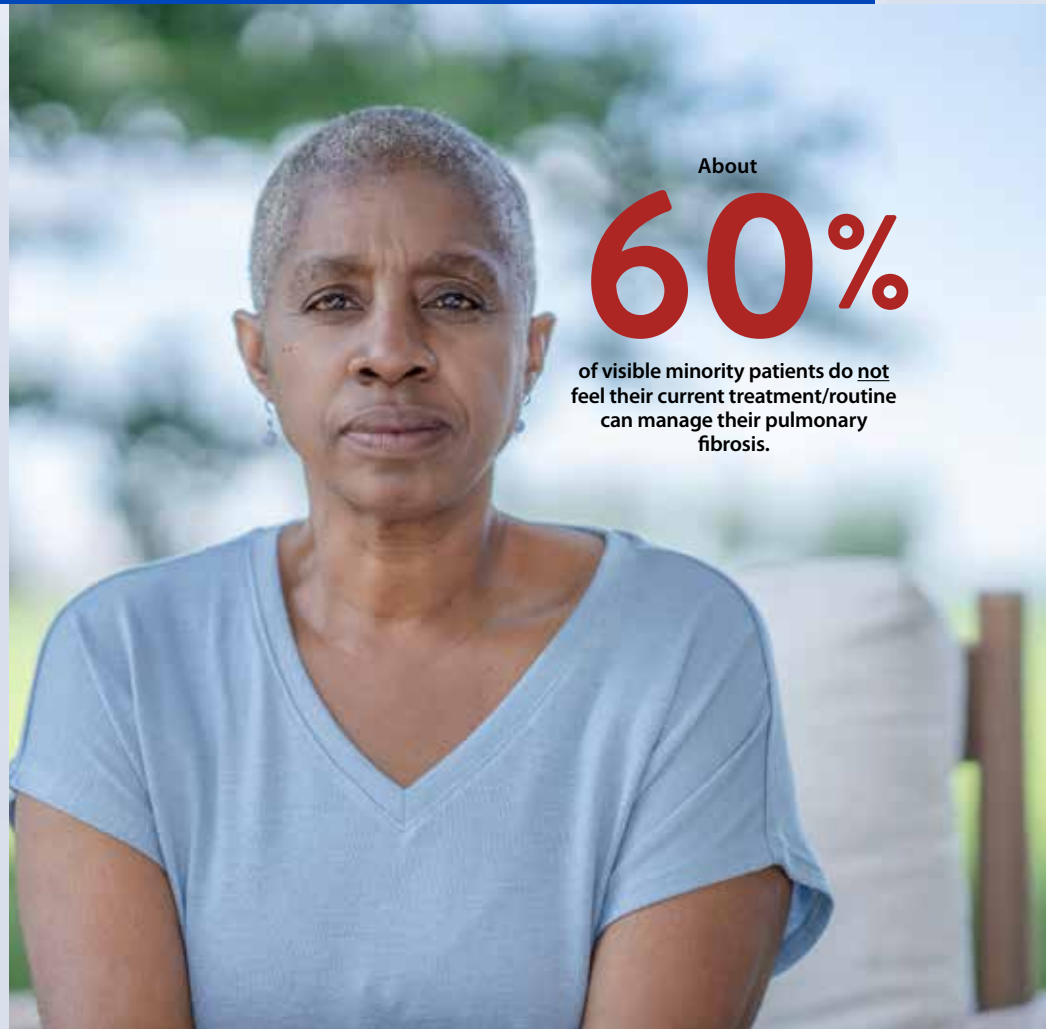
TREATMENT

People with pre-existing conditions are less likely to receive anti-fibrotics, but are more likely to receive anti-inflammatory drugs.

| PEOPLE WITH OR WITHOUT PRE-EXISTING CONDITIONS | | | |
|---|--------------|------------------------------|---------------------------|
| Treatment received | Total sample | Has a pre-existing condition | No pre-existing condition |
| Anti-fibrotic drug Ofev (nintedanib) or Esbriet (pirfenidone) | 62% | 47% | 65% |
| Anti-inflammatory drugs (e.g., Cellcept, rituximab, azathioprine) | 15% | 27% | 11% |
| Oxygen therapy | 43% | 40% | 39% |
| Physiotherapy and/or breathing exercises | 18% | 17% | 15% |
| Mental health counselling or emotional support | 6% | 6% | 5% |
| Nutritional counselling | 8% | 8% | 5% |
| Other (e.g. equipment, assistance, other drugs) | 13% | 16% | 11% |
| I am not receiving any treatments | 14% | 17% | 15% |
| Effectiveness of current treatments/routine (% agree) | 64% | 64% | 62% |

PATIENT STORY

“It took a lengthy time to get diagnosed as I got sarcoidosis due to a virus, (which) wasn’t recognized by an internist when I was first admitted to the ER... I’m in stage 4 of sarcoidosis, and only functioning on my lower lobes of my lungs at present. Breathing at the best of times is a challenge for me, I’m fortunate though as I’m not on oxygen.”



About
60%
 of visible minority patients do not feel their current treatment/routine can manage their pulmonary fibrosis.

DIRECTIONALLY*, RURAL COMMUNITIES REPORT SIMILAR ACCESS AS URBAN / SUBURBAN COMMUNITIES.



| PEOPLE LIVING IN URBAN VS RURAL AREAS | | | |
|---|--------------|------------------------|----------------------------|
| Treatment received | Total sample | Live near a major city | Live far from a major city |
| Anti-fibrotic drug Ofev (nintedanib) or Esbriet (pirfenidone) | 62% | 61% | 69% |
| Anti-inflammatory drugs (e.g., Cellcept, rituximab, azathioprine) | 15% | 15% | 21% |
| Oxygen therapy | 43% | 43% | 47% |
| Physiotherapy and/or breathing exercises | 18% | 18% | 15% |
| Mental health counselling or emotional support | 6% | 6% | 3% |
| Nutritional counselling | 8% | 8% | 5% |
| Other (e.g. equipment, assistance, other drugs) | 13% | 13% | 16% |
| I am not receiving any treatments | 14% | 15% | 10% |
| Effectiveness of current treatments/routine (% agree) | 64% | 64% | 62% |

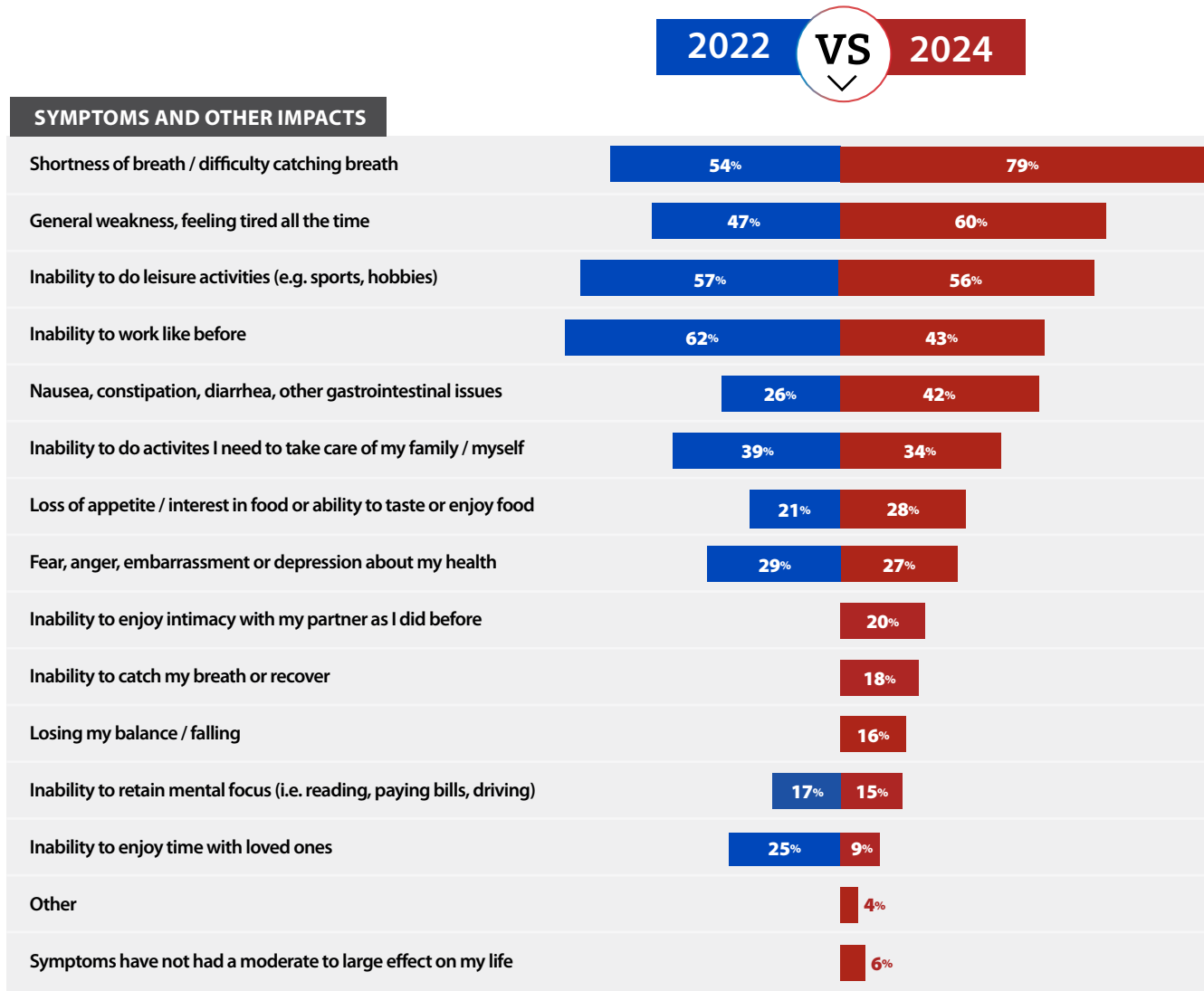
*Small sample size for rural respondents, interpret data directionally

INDIGENOUS PEOPLE RATE CURRENT TREATMENTS AS HIGHLY EFFECTIVE AND RECEIVE LESS ANTI-INFLAMMATORY DRUGS, PHYSIO, AND MENTAL HEALTH COUNSELLING.

| VISIBLE MINORITY AND INDIGENOUS PEOPLE | | | |
|---|--------------|------------------|------------|
| Treatment received | Total sample | Visible Minority | Indigenous |
| Anti-fibrotic drug Ofev (nintedanib) or Esbriet (pirfenidone) | 62% | 63% | 67% |
| Anti-inflammatory drugs (e.g., Cellcept, rituximab, azathioprine) | 15% | 31% | 0% |
| Oxygen therapy | 43% | 49% | 50% |
| Physiotherapy and/or breathing exercises | 18% | 23% | 25% |
| Mental health counselling or emotional support | 6% | 11% | 0% |
| Nutritional counselling | 8% | 14% | 17% |
| Other (e.g. equipment, assistance, other drugs) | 13% | 14% | 33% |
| I am not receiving any treatments | 14% | 9% | 17% |
| Effectiveness of current treatments/routine (% agree) | 64% | 57% | 92% |

IMPACT ON LIFE

On average, respondents selected 5 symptoms having a moderate to large impact on their quality of life. Over half of respondents cited shortness of breath, general weakness / tiredness, and inability to enjoy leisure activities.



PATIENT STORY

“Unable to access primary care appropriately. Telephone consults only. Told I had chronic bronchitis inhalers prescribed No chest X-ray done and no physical in person checkup... 6th time (in about 10 years) I had coughing, wheezing, and after 2 weeks went to Emergency hospital... oxygen levels low 70’s. Was checked for pulmonary embolus, but scarring of lungs found... Never saw a respiratory therapist in hospital... Still coughing nonstop on return home and lightheaded... Desperate @ this time. Still somewhat in shock this has happened to me. Doing my best to cope with 24/7 Oxygen, huge lifestyle change, loss of freedom and still recovering 6 months plus later.”

“The psychiatrist told me if I wanted to go for transplant to never show any depression or sadness over my condition to any of the transplant team or I wouldn’t get on the list. So not only do you have cruel diagnosis with no mental support but you get a totally unsympathetic attitude to go with it.”

PATIENT

TOP 2 SYMPTOMS HAVE INCREASED SIGNIFICANTLY SINCE THE LAST SURVEY

2022 VS 2024

Shortness of breath / difficulty catching breath

54% vs 79%

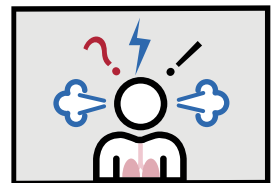
General weakness, feeling tired all the time

47% vs 60%

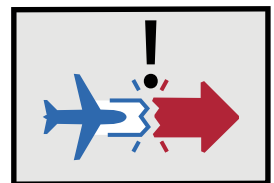
MOST FREQUENTLY MENTIONED ISSUES:



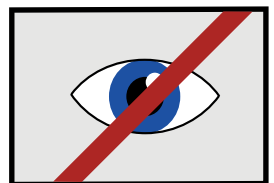
Financial impact



Mental health / worry / fear



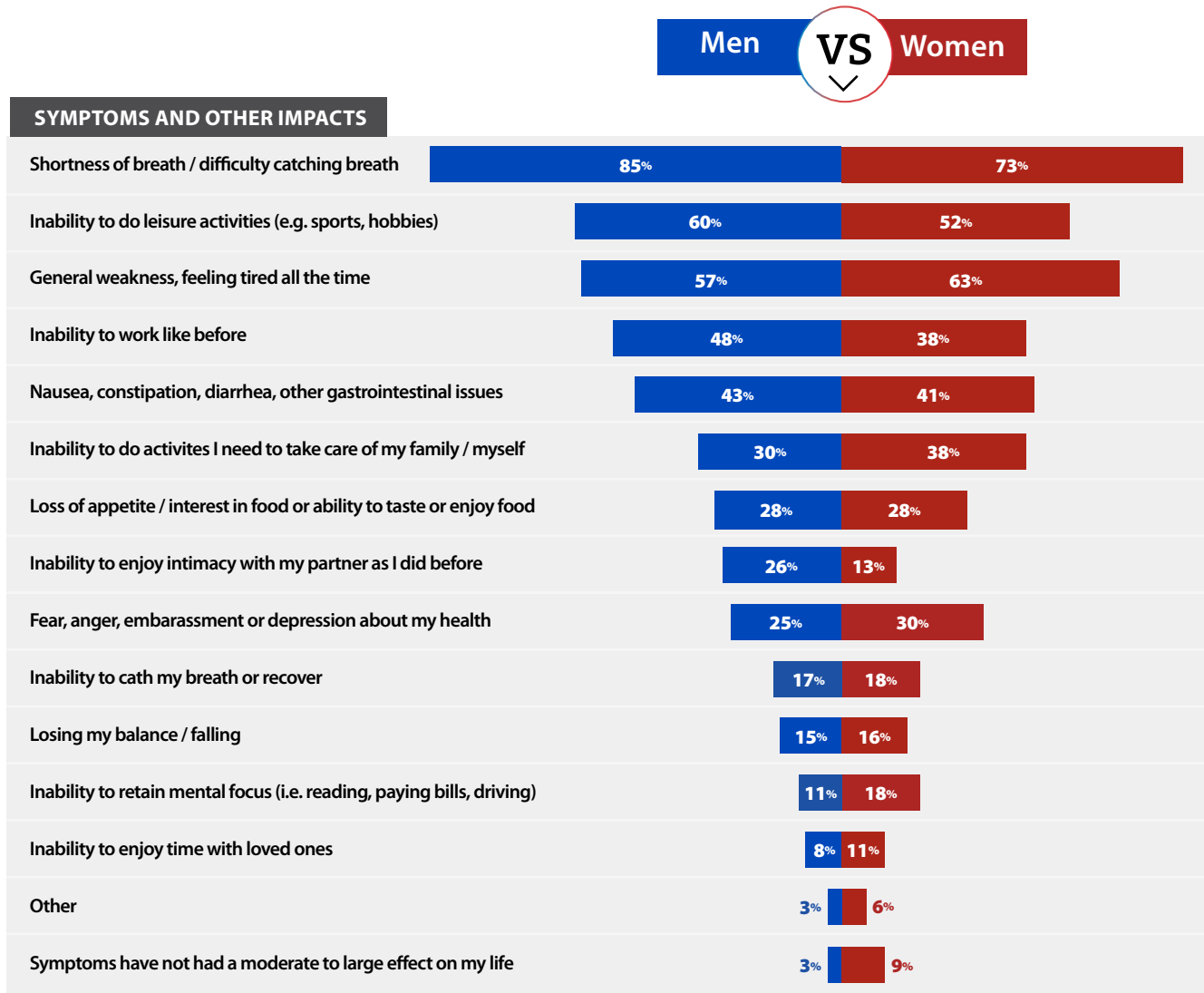
Impact on travel, socializing



Hidden disease / hard to explain

IMPACT ON MEN VS WOMEN

For symptoms that negatively impact life, men rated shortness of breath, inability to work, enjoy leisure activities or intimacy higher than women. Women cited inability to take care of her family or herself and lack of mental focus higher than men.



“Often misdiagnosed. At first there were those (health care providers) who felt I was too young to have IPF. I was even told it was in my head. It took years of chronic coughing, bouts of pneumonia, extremely impaired walking before I was diagnosed. My life completely changed.”

PATIENT



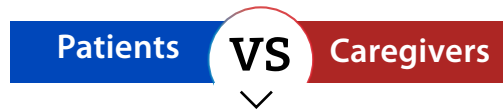
PATIENT STORY

“I had three episodes of pneumonia during Covid, which was so hard to be hospitalized as at the time there was no vaccine. After third time I ended up with the most amazing lung specialist. One of my big blocks is paying for rides to doctor appointments and help with my household chores. I am living on pension and I spend a lot of my money on prescriptions, and pharmacare doesn’t really help... I worked for over fifty years and I don’t qualify for any monetary help. Living on old age and CPP and I can’t afford food. My doctor is prescribing a new drug and I don’t think I can afford it.”

PATIENT

SUPPORTING PATIENTS & CAREGIVERS

Patients need info on research, treatments, and exercise. Caregivers want resources on O2 therapy, caregiver skills training, and self care:



| INFORMATION NEEDS BY TOPIC | | |
|--|-----|-----|
| Research & new treatment info. | 63% | 52% |
| Current treatments | 45% | 30% |
| Nutrition & supplements | 38% | 32% |
| Exercise | 39% | 38% |
| Oxygen therapy | 31% | 41% |
| Mental health support | 22% | 33% |
| Lung transplants | 20% | 16% |
| MAID | 18% | 16% |
| Discussing illness with & family & friends | 17% | 14% |
| Communicating with healthcare team | 16% | 14% |
| Advance Care Planning | 13% | 13% |
| Resources / Caregiver skills training | 9% | 29% |
| Caregiver self-care | 8% | 36% |
| Financial planning | 5% | 12% |
| Estate planning | 3% | 3% |
| Other | 2% | 7% |

“ You have to do all the research yourself... there are a lot of things out there that could potentially help or help manage the symptoms... no one seems to understand in the medical field how difficult the cough is.”


PATIENT

“They just tell you what you have, what you need to do to get on transplant list , put you on drugs and then you’re on your own. You become your own advocate looking for help wherever you can... trying to decipher off the internet what is real and what isn’t.”

PATIENT



FROM INSIGHT



TO ACTION

CPFF’s **Support Groups** provide patients and caregivers access to an important source of information and expertise for people at every stage of the disease – each other.

Men **VS** Women

Our research revealed some real differences in information needs and preferences of women and men survey respondents.

INFORMATION SOURCES (PATIENTS)

84% vs 76% **52% vs 61%**

Respirologist / Lung doctor

CPFF website

18% vs 22% **16% vs 13%** **16% vs 20%** **11% vs 21%**

CPFF support group

Family doctor

Other medical website

Other patients

Women rated nutrition & supplements, mental health, discussing their pulmonary fibrosis and advanced care planning higher than men:

| TOPIC | Men | Women |
|--|-----|-------|
| Research & new treatment info. | 63% | 63% |
| Current treatments | 47% | 44% |
| Exercise | 38% | 32% |
| Nutrition & supplements | 34% | 44% |
| Oxygen therapy | 32% | 30% |
| Lung transplants | 21% | 19% |
| MAID | 17% | 19% |
| Mental health support | 15% | 29% |
| Communicating with healthcare team | 14% | 18% |
| Discussing illness with & family & friends | 13% | 21% |
| Resources / Caregiver skills training | 8% | 10% |
| Caregiver self-care | 8% | 18% |
| Advance Care Planning | 8% | 9% |
| Financial planning | 4% | 3% |
| Estate planning | 4% | 6% |
| Other | 0% | 4% |
| None of the above | 7% | 3% |

PATIENT STORY

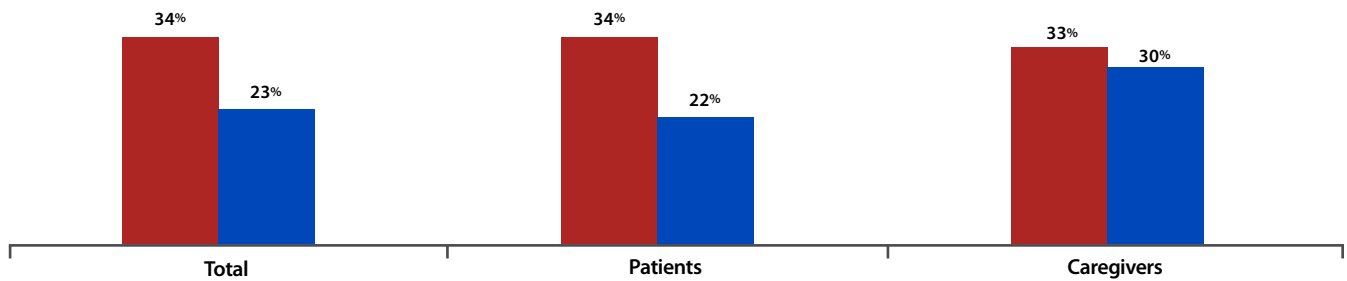
“The respiratory doctor blurted out his diagnosis of IPF handed me a brochure on OFEV and sent me on my way with no explanation of what I had or the severity of the disease. I had to Google IPF when I returned home to understand the severity...that there was no cure etc. There is no support from the doctor’s office other than your six month 10 minute appointment. I would be better off with lung cancer as cancer has lots of support...”

SUPPORT GROUPS

After a dip due to COVID-19, support group participation, particularly among patients, has risen significantly.

2024 VS 2022

PARTICIPATION GROWTH





About 2 in 5 patients would be interested in knowing more about support groups or programs, and about 1 in 4 caregivers.



| PATIENT AND CAREGIVER PARTICIPATION & INTEREST | |
|---|--|
| Yes, I am in a support group | <div style="display: flex; justify-content: space-around;"> <div style="background-color: #0056b3; color: white; padding: 5px;">33%</div> <div style="background-color: #a52a2a; color: white; padding: 5px;">34%</div> </div> |
| No, I am not in a support group but am interested in knowing more | <div style="display: flex; justify-content: space-around;"> <div style="background-color: #0056b3; color: white; padding: 5px;">28%</div> <div style="background-color: #a52a2a; color: white; padding: 5px;">43%</div> </div> |
| No, I am not interested | <div style="display: flex; justify-content: space-around;"> <div style="background-color: #0056b3; color: white; padding: 5px;">38%</div> <div style="background-color: #a52a2a; color: white; padding: 5px;">32%</div> </div> |

“Caregiving is a challenge... The caregivers support group has a huge impact. To know that others are experiencing what you are. Our friends have been a great support as well.”

A BREATH OF HOPE

CPFF's ongoing surveys, which fuel our advocacy work, demonstrate that when patients' and caregivers' voices are heard, positive change can happen. As seen in this report, diagnosis time is trending downwards, new medications and other promising research are on the horizon. As more of the public and medical community become aware of PF it is our hope that earlier detection, more promising treatments, and ultimately a cure will be within reach.

The Canadian Pulmonary Fibrosis Foundation is committed to working harder than ever in the future to keep pushing tirelessly to achieve our vision of a world without pulmonary fibrosis.



FROM INSIGHT TO ACTION

EARLY DIAGNOSIS

1

We will...

continue to educate the public and medical community on early signs and symptoms of pulmonary fibrosis in order to ‘tackle the crackle®’, including for people with pre-existing conditions.

NEW TREATMENTS

2

We will...

continue to inform pharmaceutical companies on patient needs, advocate for less intrusive side effects, champion more clinical trial access in Canada, and work with governments to expedite approvals of new treatments.

PATIENT AND CAREGIVER SUPPORT

3

We will...

continue to build awareness by sharing patient and caregiver stories, and will support patients and their families every step of the way through their PF journey. We will also advocate for equitable access to treatment for all Canadians.





Canadian
Pulmonary Fibrosis
Foundation

Canadian Pulmonary Fibrosis Foundation

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