

PULMONARY FIBROSIS CAREGIVER GUIDE



Canadian
Pulmonary Fibrosis
Foundation

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WARNING SIGNS OF A BREATHING EMERGENCY

If the patient is having some of the following symptoms: **CALL 911**

- | | |
|-------------------------------------------------------------------|---------------------------------------------|
| <input type="checkbox"/> Very rapid breathing | <input type="checkbox"/> Pale, greyish skin |
| <input type="checkbox"/> Extreme tiredness/lethargy or drowsiness | <input type="checkbox"/> Sweating |
| <input type="checkbox"/> Sudden worsening shortness of breath | <input type="checkbox"/> Chest pain |
| | <input type="checkbox"/> Confusion |

SHOULD WE CALL THE DOCTOR?

Make an appointment if the patient has:

- Worsening breathing / shortness of breath
- Increased cough
- Changes to sputum production
- Fever
- Appetite changes
- Generally feeling unwell

BEING A PF CAREGIVER

YOU'RE NOT ALONE

Who are pulmonary fibrosis (PF) caregivers? According to CPFF's 2024 *CPFF Patient and Caregiver Survey*, 97% are a family member of the patient, usually a spouse, and two-thirds are over the age of 70. While it can be rewarding to support someone who is living with this progressive disease, it can also be both physically and emotionally draining.

At times, it can feel overwhelming. There is the lack of predictability around disease progression, caring for your loved one's (*and your own*) physical and mental health needs, explaining to others the limitations of a little-known condition, navigating the healthcare system... to name a few. It is perfectly normal for you to experience many emotions, mourning what was, and accepting what is. Life will be different than before, but it's still possible to find hope, good times, and a supportive community.

We know from our survey, through the stories we hear in support groups, and in personal conversations the many challenges PF caregivers face. We created this guide as a companion publication to the *CPFF Pulmonary Fibrosis Patient Guide* to help you be an effective caregiver and patient advocate while taking care of yourself, too.

Knowledge is power, and anxiety can be lessened with planning and by reaching out for help. In this guide, we offer you education, tips, and support. Please know that **you are not alone**.

Scan the code to view the CPFF Pulmonary Fibrosis Patient Guide



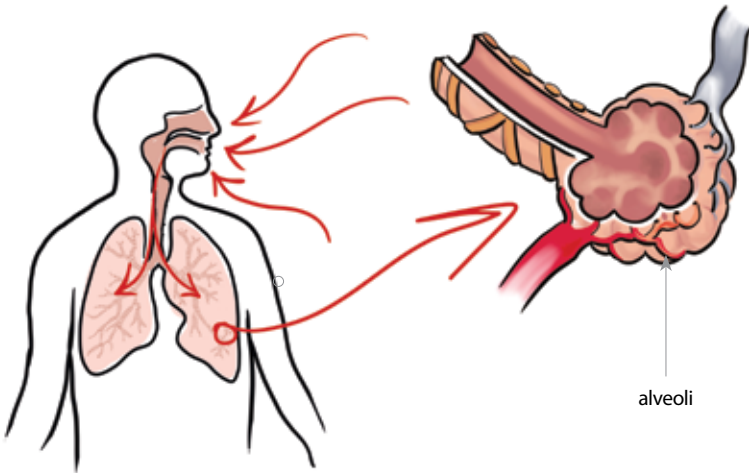
HOW TO "SCAN" A QUICK RESPONSE (QR) CODE

Open the Camera app on your phone. Hold your phone so that the QR code appears in view.
Tap the notification to open the link associated with the code.

WHAT IS PULMONARY FIBROSIS?

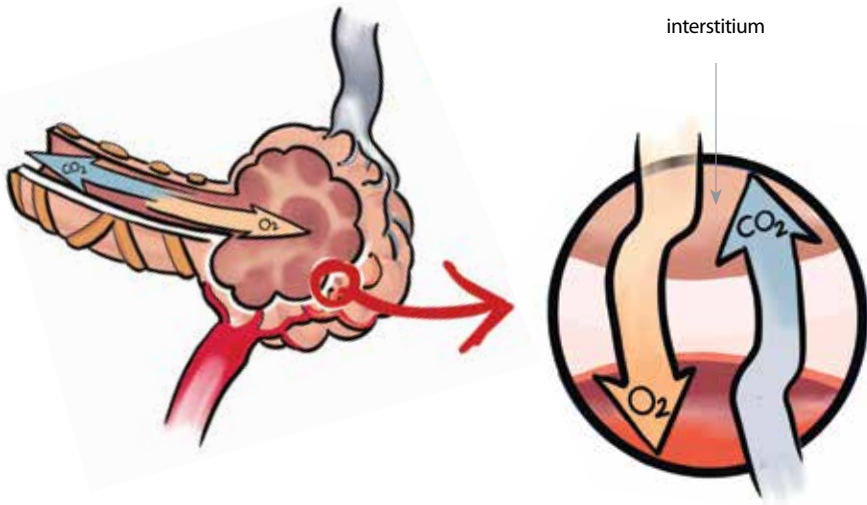
THE BASICS

Pulmonary fibrosis (PF) is the common term used to describe a family of more than 200 different lung diseases that cause scarring (**fibrosis**) in the lung (**pulmonary**). The PF family of lung diseases falls into a larger group called *interstitial lung disease (ILD)*, which cause inflammation and/or scarring in the lung. Over time, scarring destroys normal lung tissue, depriving the blood of needed oxygen. This can cause shortness of breath, especially when walking or exercising. An estimated 30,000 Canadians live with pulmonary fibrosis. About half of these have idiopathic pulmonary fibrosis (IPF), meaning the cause is unknown. It is important to know what kind of pulmonary fibrosis the patient has, as this affects breathing, disease progression, and recommended medications.



The interstitium is the part of the lung that holds all of the structures together—think of it as the scaffolding of the lung.

If we zoom in, we can see the airways. At the end of these airways are air sacs called **alveoli**.



In healthy lungs, oxygen (O₂) enters the air sacs, crosses the **interstitium** and diffuses into our blood vessels. Carbon dioxide (CO₂) - our waste gas - diffuses out of the blood into the alveoli.

With interstitial lung disease (PF) there is **inflammation and scarring of the interstitium**. It thickens and impairs the flow of O₂ into the body.

TREATMENT

There is limited awareness of PF among the public and even health-care professionals. Early symptoms of PF are frequently diagnosed as less-serious conditions at first, so a delayed PF diagnosis, unfortunately, is not unusual. However, as most medications work by slowing disease progression, **the sooner treatments can start, the better** to stabilize the patient as early as possible.

LIFE EXPECTANCY

Prognosis varies depending on the patient's age, general health, treatments, and other factors. Exciting new research is on the horizon. Do **NOT** rely on unvetted online information – it's most likely incorrect.



Scan the code to learn more about Pulmonary Fibrosis

BEING THE PATIENT'S ADVOCATE

SUPPORTING THE PATIENT

By being the patient's advocate, you are playing a vital role. This means being there every step of the way, and using your voice when needed to ensure they receive the best possible care. *(Read the Pulmonary Fibrosis Patient Charter of Rights, p.20)*

STAYING UP-TO-DATE

There is a lot of outdated and incorrect information online. Check CPFF's website for vetted resources and sign up for the CPFF newsletter to keep up with the most up-to-date information.



BUILDING YOUR TEAM

Your team is everyone who will support the patient, and you as their caregiver, along your journey. Many caregivers take on the role of coordinator. The task can seem overwhelming. The key is to be organized, proactive, and persistent.



MEDICAL APPOINTMENTS

Before an appointment, write down any questions and concerns to raise with the doctor. During the appointment take notes. Be an extra set of ears and ask questions the patient may be hesitant to raise. Speak up for your loved one, but don't forget to let them express any worries they may have, at their own pace.

“It’s not just the patient... it’s really caregivers and families that are also having this lived experience”

DR. CHARLENE FELL
RESPIROLOGIST, CALGARY, AB



Consider bringing the questions below to the patient's next appointment. Ask about treatments that can reduce the decline in lung function and help slow disease progression. Work with the doctor to maintain the best quality of life possible.

QUESTIONS FOR THE DOCTOR

- 1) *What can we expect as the disease progresses and what adaptations should we make in our household?*
- 2) *How can the patient's symptoms be managed?*
- 3) *Can lifestyle changes (i.e. diet, exercise, relaxation techniques) help?*
- 4) *What treatments can help slow disease progression?*
- 5) *When is it time for supplemental oxygen?*
- 6) *When is the right time to start medication?*
- 7) *What are the benefits of starting treatments sooner?*
- 8) *What resources and support programs are available?*

NOTES:

PF CAREGIVING 101

CHALLENGE

MANAGING EXPECTATIONS

Pulmonary fibrosis is an unpredictable disease. Your loved one will have good days and bad days. There may be a sudden change in their condition – what was possible before may no longer be feasible today. Some household chores may become too difficult.

SOCIAL ISOLATION

It's not unusual for someone with PF to be wary of outings and travel. This is understandable, as there are several reasons to avoid leaving the comfort and safety of home; fear of lacking sufficient O₂, fear of infections, and for some, feelings of embarrassment.

GETTING SICK

No one likes to get sick, but for someone with pulmonary fibrosis, upper respiratory illnesses in particular are best avoided, as an infection can have serious implications. It's important to avoid exposure to colds, flus, and other infectious disease.

OXYGEN THERAPY EQUIPMENT

Relying on medical equipment and devices to breathe – it's easy to be intimidated.





COPING STRATEGY

BE FLEXIBLE

Planning is necessary when living with PF. Expect the unexpected to avoid disappointment or frustration when things don't go as planned. Go with the flow, it's okay to change up your routine. For household chores, discuss who will do what going forward.

BE PREPARED

Outings and travel are still possible for a fulfilling life. Take a pulse oximeter and needed medications along. Know how much portable oxygen you'll need and where you can get more.



pulse oximeter

PROTECT YOUR HEALTH

Anyone in close contact with the patient should take precautions. Avoid sick people and large crowds, or consider masking. Stay up to date with immunizations, wash hands often or use hand sanitizer. Stop smoking, enjoy a healthy diet, and exercise regularly.

GET EDUCATED

Oxygen therapy machines and devices are relatively simple, robust, and widely used. Providers typically provide in-person training, a large capacity spare cylinder to use in the event of a power outage, a detailed user's manual, and 24/7 telephone technical support.



Scan code to
learn more about
pulmonary
fibrosis

PF CAREGIVING 101

CHALLENGE

BALANCING WORK AND CAREGIVING

If you are working outside the home or are caregiving at a distance, there is an extra layer of pressure to contend with. It can be harder to deal with the demands of caring for someone with PF.

FINANCIAL CONCERNS

Talking about money can be tricky, but the reality is finances are often impacted when living with pulmonary fibrosis, for both patient and caregiver. Treatments, therapies and programs are not always covered. Future care needs must also be considered.



MEDICAL EMERGENCIES

Some patients will experience what is referred to as an **acute exacerbation**. This occurs when there is a triggering event that results in a sudden increase in the processes that lead to scarring. As the lung scarring gets worse, patients have a harder time breathing. The damage to the lungs during an acute exacerbation is permanent. During an acute exacerbation, many patients require hospitalization.



If the exacerbation is severe, the patient may require ventilator support. It is not always clear what causes an exacerbation. If the cause is an infection, it may be treated with antibiotics. Otherwise, doctors will provide supportive care—for example, extra oxygen.



COPING STRATEGY

SELF-ADVOCATE

Explain your situation. As it's likely your employer hasn't heard of PF, be prepared to explain the challenges you are facing. You may also be eligible for caregiver benefits and leave. *(scan code below)*

BE PROACTIVE

There are several financial supports available for caregivers from both provincial and federal government agencies. In addition, completing personal income tax on a yearly basis can increase the opportunity for potential government credits or benefits.



Scan the code to learn more about financial supports and programs

STAY CALM

Knowledge is power. The more you know about how to avoid medical emergencies, the better. That being said, they sometimes do happen. Consider discussing the patient's wishes in advance should they not be able to speak for themselves during a medical emergency. *(see Advance Care Planning, p.17)*

If a medical emergency occurs, try and stay calm. This will help the patient to calm their breathing. Keep a detailed list of needed medications and other vital health information ready in case of a hospitalization.



CAREGIVER STORIES

BE ALERT FOR EARLY SIGNS SAYS CAREGIVER BILL



“ While caring for Jackie, I learned that I was stronger than I thought.”

BILL BRADSHAW

Bill and Jackie in Australia in 2019, a year after her diagnosis of idiopathic pulmonary fibrosis.

Looking back now, Bill Bradshaw, 76, recalls the early signs of his wife Jackie’s pulmonary fibrosis.

“She’d had a knee replacement and was understandably having trouble walking up hills and dealing with the stairs in our three-storey home. But, it wasn’t just muscle or joint pain. She was out of breath and would have to stop and rest,” he says.

After a round of tests in the emergency department, they got some news. She had a hiatal hernia, which was treatable, and she had pulmonary fibrosis. They were told to have their GP refer them to a respirologist.

It was 2018 when Jackie had her first appointment with a respirologist who confirmed a diagnosis of IPF (*idiopathic pulmonary fibrosis*). Bill was with her.



CAREGIVING FOR A HUSBAND WITH SLOW PROGRESSING PF

“I think it’s important for him to keep doing what he is able to do.”

CAROLYN MORTON



Dale collects sap for maple syrup from one of his 17 trees.

Carolyn Morton, 74, has seen her husband Dale, 76, cope quite well during his 11-year journey with IPF that, fortunately for them both, has progressed very slowly. She sees her main caregiver role as a morale booster, keeping Dale’s spirits up and giving him a pep talk now and then.

The day we spoke, Dale was out on their property in Hammond Hills, Nova Scotia, just outside Halifax, collecting sap for maple syrup from the 17 trees he had tapped. He needs oxygen only for exertion – when he’s walking or exercising. One of the couple’s two sons, who lives with them, helps Carolyn with shovelling snow, but Dale has yet to relinquish his snow blower.

“I think it’s important for him to keep doing what he is able to do. The stairs are difficult, so we’ll help him bring firewood upstairs. And he’s always been helpful around the house and with child care, so now we enjoy our five grandchildren together.” These days, Dale makes jam and together they make fruitcakes.



Caregiving from two perspectives:
Brad Bjorgum's wife Heidi and daughter Sandi



*“ ...we'll
continue to find
the acceptance,
the joy, and the
love this world
and the
beautiful people
in this world
have to offer ”*

HEIDI SCHOLLENGBERG

Brad and Heidi enjoying a walk with family.

HEIDI'S STORY

GRIEVING FOR WHAT WAS AND FINDING ACCEPTANCE FOR WHAT IS

Heidi Schollenberg is a pastor's wife, a mother, grandmother, an oncology nurse, still working, and now her husband Brad's caregiver. She was 15 when they started dating and they just celebrated their 40th wedding anniversary this past June.

Brad was diagnosed in February 2022 with moderate disease idiopathic pulmonary fibrosis. The year their lives changed forever. Their life instantly took a 180 degree turn and Heidi was nervous and afraid and trying to be brave.

With honesty and candour, Heidi shares their journey through a life changing pulmonary fibrosis diagnosis, medications, support groups, preparing for lung transplantation, and finding joy wherever they can.





Sandi Bjorgum with her dad.

SANDI'S STORY

FINDING HOPE & HEALING AS A PF CAREGIVER

Sandi Bjorgum was overcome with grief and shock when her father was first diagnosed with PF. He had always taken care of her, but now it was her turn to take on the role of caregiver. Sandi shares her heartfelt story of fear, courage, acceptance, and hope as she supports her dad in his new normal.

“What has living with IPF been like? I say this like I am the one who has been diagnosed, which I am not, but rather it feels as though this diagnosis has impacted my life just the same. As a caregiver, we are so closely tied to this disease, to the pains, to the struggles, to the grief, to the difficulties, to the medical appointments, to the follow-ups, the questions and decisions”, says Sandi.

“It’s like I am the one who has been diagnosed, which I am not, but rather it feels as though this diagnosis has impacted my life just the same.”

SANDI BJORGUM



Scan code to
hear Sandi's story

TAKING CARE OF YOU

YOU NEED TO BREATHE, TOO

Being a caregiver is hard. Over time it can take a physical and emotional toll. Consider this – in air travel, in the event the airplane cabin is depressurized, safety protocols advise parents to put on their own oxygen mask *before* the child's. This is an apt metaphor for caring for someone with PF. You can best care for them if you take good care of yourself.

ASK FOR (AND ACCEPT) HELP

You don't have to do it all. Ask for and accept the help of other family members, friends, or neighbors. Let them know what's needed – running an errand, mowing the lawn, preparing a meal, etc. People often want to help, but are unsure of what to do.

TIME FOR YOURSELF

Can a friend or family member stay with the patient once a week, or once in a while? If they haven't been in your shoes they may not realize how much offering you a bit of respite can help you recharge your batteries. Is there an adult daycare, drop-in or respite care service in your community that can give you a break?

STAY CONNECTED

Try to keep doing the things that are important to you – hobbies, social connections, and friendships are all important as before. Many people find that connecting with other PF caregivers who share similar experiences brings them comfort, support, and hope. *(Check out CPFF support groups, p. 16)*

STOP SMOKING

If the PF patient, you or anyone in the household is a smoker, now would be the time to stop. Even second-hand smoke is harmful for someone with pulmonary fibrosis.



IMMUNIZATIONS

Everyone in the household should be up-to-date with immunizations, such as flu, pneumonia, shingles, and COVID-19.



EAT WELL

Give your immune system a hand by eating a balanced diet with plenty of fresh fruits, vegetables, legumes, lean protein, and whole grains.



EXERCISE

There are so many benefits to getting regular exercise. If you and the patient were exercising before, now is not the time to stop! It helps keep you healthy and is a great mood-booster. Talk to your doctor before starting a new exercise routine.



DEALING WITH STRESS

Consider exploring stress management techniques like yoga, meditation, or deep-breathing exercises. There are many excellent free videos online, or try a relaxation smartphone app. Maybe there is a class or group in your community you can join.



FIND SUPPORTIVE LISTENERS

Try and establish a network of people such as friends or family you can talk to when things are hard. You can also benefit from speaking to a counsellor, hospice nurse, palliative care social worker or therapist with experience supporting people with life-limiting conditions.

It can be challenging to find other people who relate to what you are going through. Family and friends may not understand the impact of the disease. Feelings of isolation are common. CPFF hosts free virtual patient support groups as well as dedicated caregiver support groups to bring together people with similar experiences to share their feelings, coping strategies, and more.

“ ... the facilitators and members are very caring and supportive of all of us in our trials along the way. Everyone has a different story and we have learned so much from each other and the facilitators. We are not alone in our journey.

I am very thankful to have found this group and highly recommend joining them.”



CAROLYN MORTON
CPFF Caregiver
Support Group Participant



Scan code to find PF
support groups

HAVE A PLAN

WHAT IS AN ADVANCE CARE PLAN (ACP)?

Advance care planning is a process of reflection and communication. A time for you to reflect on your values and wishes, and to let people know what kind of health and personal care you would want in the future if you were unable to speak for yourself.

It may help to think of advance care planning as part of your “life” plan. Just as you plan for financial goals, buy insurance, and write a will, you should have a plan for your health care. Like these other plans, your ACP will change as your life changes: when you get married, have children, retire, undergo major surgery, or are diagnosed with a chronic illness such as PF.

Having an advanced care plan is also helpful for health care professionals. In a moment of crisis, ACP helps everyone; the patient, family members and health care professionals are better prepared, and hopefully in agreement, since this is not the first time that everyone involved has thought of this possibility.

Learn about advance care planning in CPFF’s webinar featuring Karine Diedrich of the Canadian Hospice and Palliative Care Association. In this webinar Karine discusses the five steps of advanced care planning: *Think, Learn, Decide, Talk, and Record*.



STEP 1
THINK



STEP 2
LEARN



STEP 3
DECIDE



STEP 4
TALK



STEP 5
RECORD



Scan code
to watch the webinar

Learn more: CPFF.ca

CHARTER OF RIGHTS

- 1** Right to equal levels of the best **standard of care** across Canada.

- 2** Right to standardized **medical qualifying criteria** for treatments based on PF patients' unique needs.

- 3** Right to timely and accurate PF **diagnosis** and prioritized care involving skilled specialists and a multi-disciplinary care team.

- 4** Right to **integrated clinical networks** and community health services, including timely access to PF-specific treatments.

- 5** Right to aligned provincial and territorial **reimbursement policies** for PF patients reflecting Canada's commitment to accessible, universal healthcare.

- 6** Right to accurate **information** about PF, including treatments, clinical trials, support, and lung transplantation.

- 7** Right to benefit from increased investment into **PF research** reflective of the growing impact of the disease in Canada.

- 8** Right to dedicated in-person or remote **peer support networks** for patients and their caregivers.

- 9** Right to rapid **urgent care** for patients with exacerbations and disease progression, and appropriate prioritization on transplant waiting lists.

- 10** Right to compassionate **palliative** and **end-of-life** care.



ABOUT CPFF

The Canadian Pulmonary Fibrosis Foundation is a registered charity established in 2009 by Robert Davidson. We improve the lives of Canadians living with pulmonary fibrosis by providing compassionate support, leading advocacy, raising awareness, funding research, and inspiring hope.

Our vision is a world without pulmonary fibrosis.



For more information, please contact:
info@cpff.ca or 905-294-7645

Donate now to help us create more valuable resources [like this guide!](#)



Scan code
to make a donation

SUPPORT



EDUCATE



RESEARCH



ADVOCATE



RESOURCES



CPFF.ca has aggregated a wealth of resources to support family members, partners, friends, neighbours, and any other people who shoulder the physical and emotional support for people living with pulmonary fibrosis:

CAREGIVER RESOURCE LIBRARY

- Disability benefits and financial help
- CPFF virtual caregiver support groups
- Caregiver groups and organizations
- Educational videos and webinars for caregivers
- Caregiver articles and stories
- Caregiver courses
- Health information and paperwork management
- Chronic lung disease trajectory
- Legal matters
- Home safety
- Caregiver advocacy resources
- Technology aids & tools
- Advance care planning
- Palliative care
- American caregiver resources



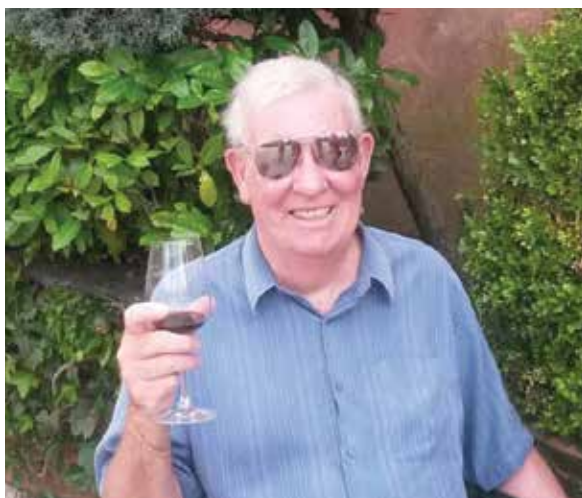
Scan to connect to the caregiver resource library

THANK YOU!

Special thanks go out to our community of healthcare professionals for their invaluable ongoing contributions to CPFF resources.

A heartfelt thank you to the CPFF Caregiver Support Group for your vital insights and experiences, which inspired the creation of this guide.

Most of all, to all the individual Caregivers for all that you do: we see you, we are here to support you, and as long as there are Canadians living with Pulmonary Fibrosis we will never stop fighting for you and your loved one.



ROBERT DAVIDSON
Founder, Canadian Pulmonary Fibrosis Foundation

DEDICATION

The CPFF Pulmonary Fibrosis Caregiver Guide is dedicated to Robert Davidson, who lived with IPF, and his family. Robert, who wrote the first edition of CPFF's Patient guide, died peacefully in 2019, nine years after his double lung transplant.



**Canadian
Pulmonary Fibrosis
Foundation**

The Canadian Pulmonary Fibrosis Foundation works tirelessly to bring the latest news about PF research, resources and more to people living with PF as well as the larger community. Please visit our website:

cpff.ca



Canadian Pulmonary Fibrosis Foundation

For more information, please contact: info@cpff.ca

Charitable Registration # 850554858RR0001



Scan the code
to connect to cpff.ca