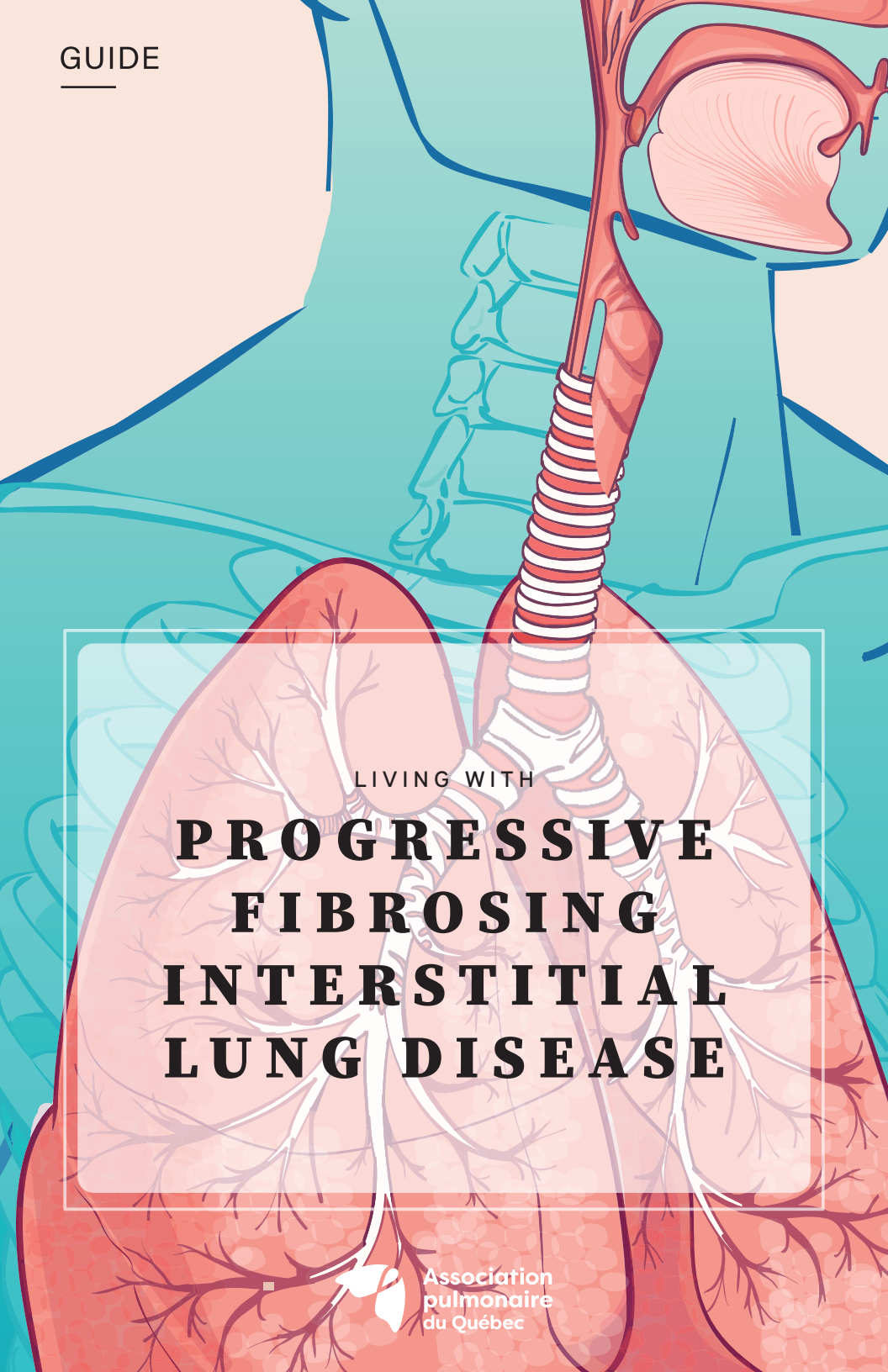
GUIDE



LIVING WITH

PROGRESSIVE FIBROSING INTERSTITIAL LUNG DISEASE

Association pulmonaire du Québec

ONE STEP AT A TIME

A diagnosis of progressive fibrosing interstitial lung disease causes real upheaval in the lives of people suffering from the disease, and their loved ones. However, there are many things you can do to stay in control of your emotions and continue enjoying life to the fullest.

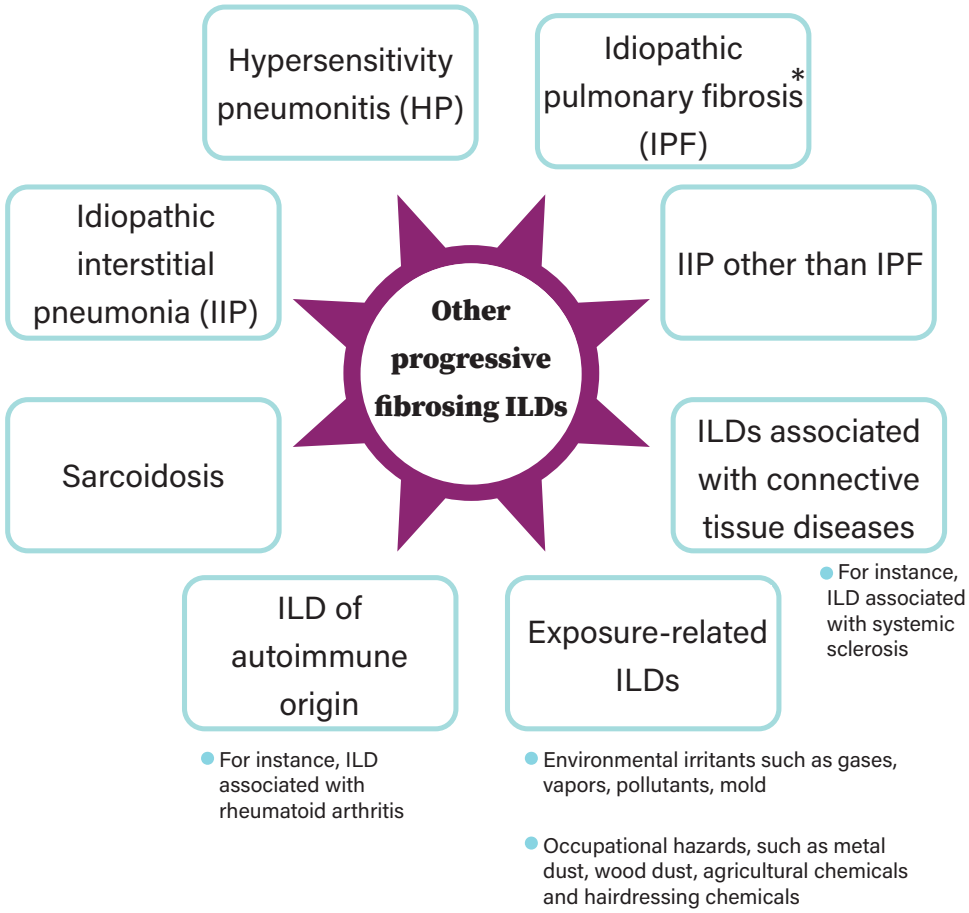
Over the next few weeks or months, you will be discussing your care journey with your medical team. An important first step is to learn as much as possible about progressive fibrosing ILD. The goal is to understand how the disease can impact you, whether today or tomorrow, and what you can do to reduce the effects.

What is progressive fibrosing ILD?

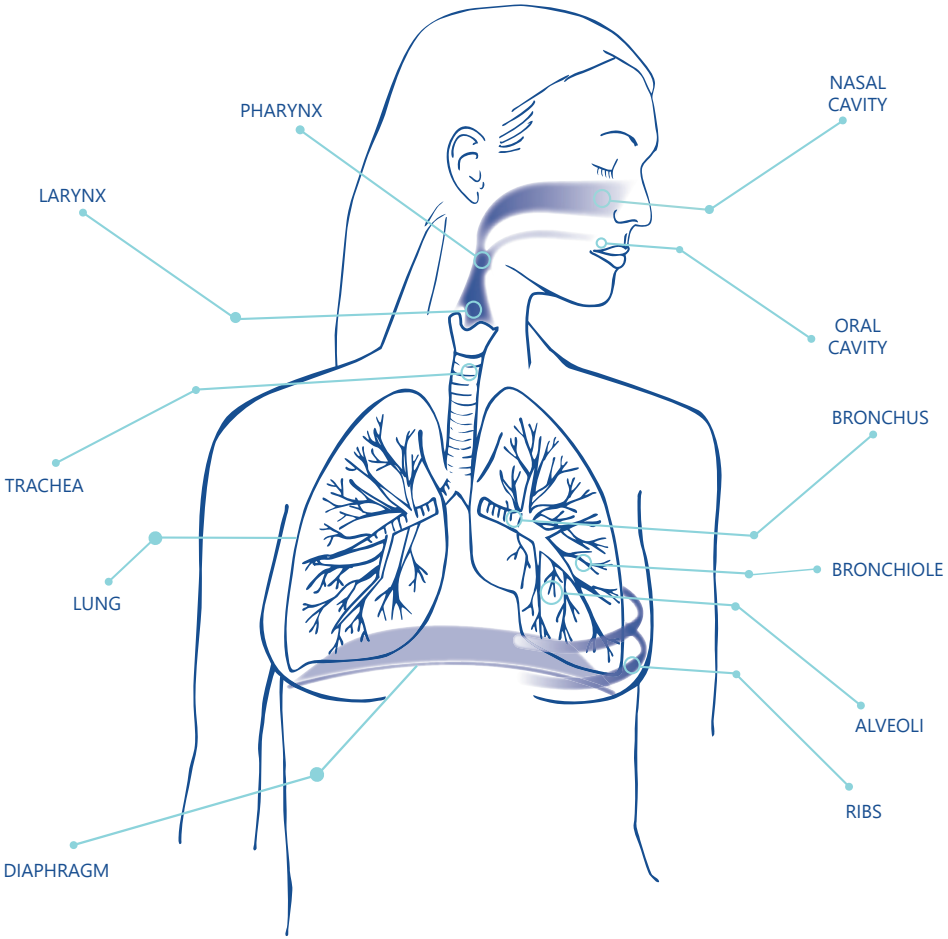
Interstitial lung disease (ILD) is a term that encompasses a broad group of lung diseases that result in scarring (fibrosis) of the lungs. This causes the lung tissue to stiffen.

For many people with ILD, the scarring or fibrosis can continue to worsen i.e. the disease progresses. Your doctor may have already told you that you have one of the following conditions.

*Idiopathic pulmonary fibrosis (IPF) is the accumulation of scar tissue in the lungs due to an unknown cause. However, studies conducted on the population diagnosed with this disease show that there seems to be some common risk factors. Smoking, exposure to environmental pollutants and lung infections are common in people with IPF. Many patients also have gastroesophageal reflux, although the relationship between these two conditions is still not well understood. Finally, genetic factors may be linked to the development of IPF. There are occasionally cases of familial pulmonary fibrosis.



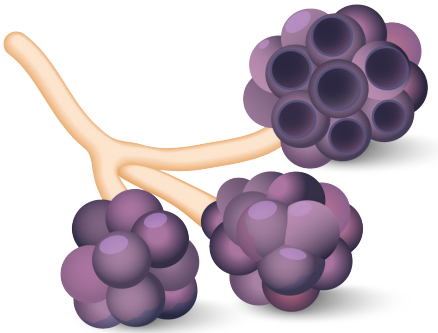
Changes observed in the lungs of people with progressive fibrosing ILD



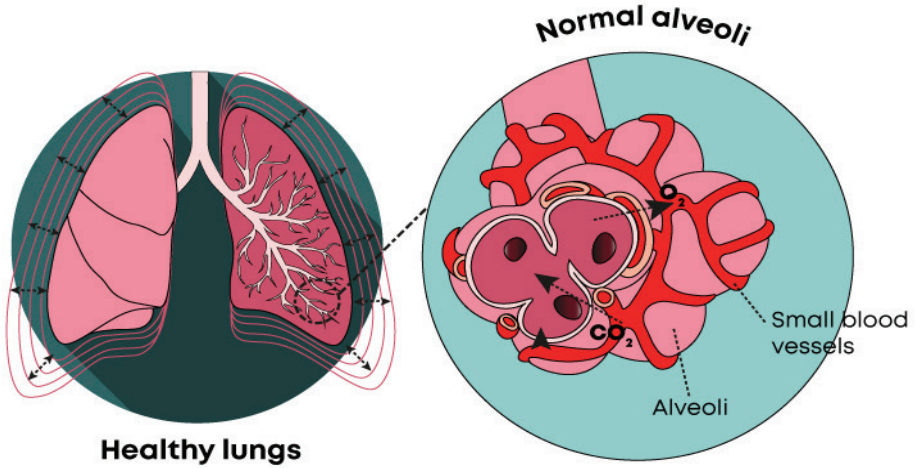
The main airways inside the lungs are called bronchi. They subdivide into smaller and smaller airways called bronchioles. At the ends of the bronchioles are small air sacs called alveoli.

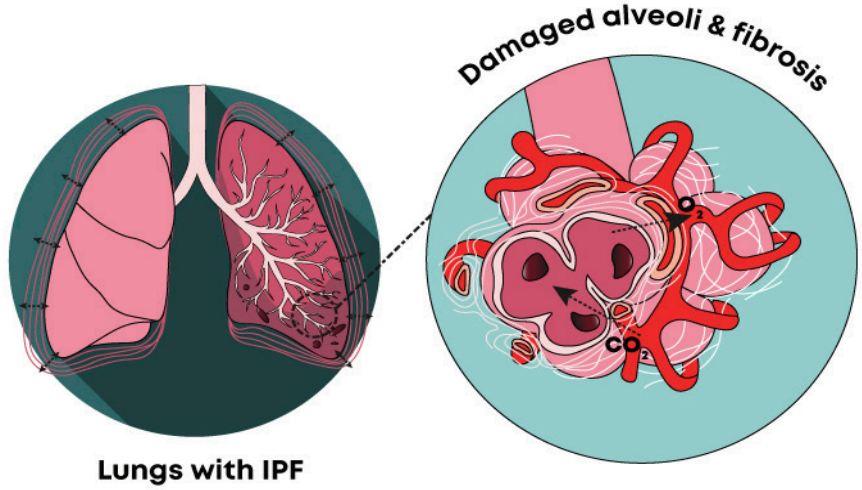
Each alveolus is surrounded by blood vessels connected to the body's bloodstream. Thus, the alveoli and the blood vessels that surround them supply all other parts of the body with oxygen.

When fibrosis occurs, the accumulation of scar tissue irreversibly damages the bronchioles and alveoli. Healthy lungs are flexible and elastic: they inflate and deflate easily and allow oxygen to be carried to the blood and carbon dioxide (CO_2) to be expelled from the body. In fibrotic lungs, the damage makes it difficult for oxygen to enter the bloodstream, causing both shortness of breath and an insufficient supply of oxygen to the organs to ensure their normal function.

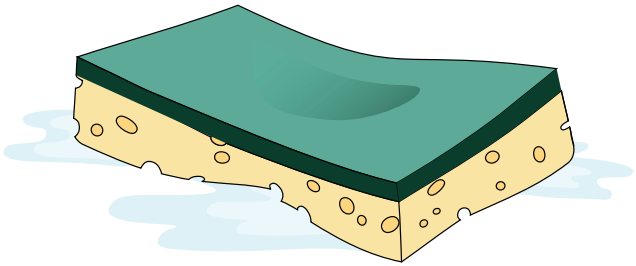


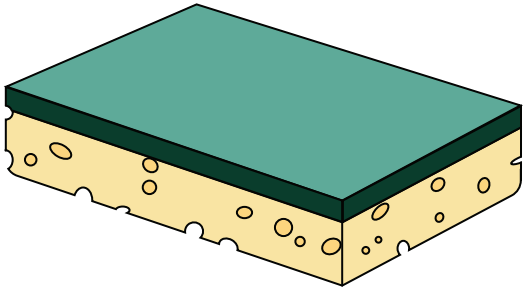
PROGRESSIVE FIBROSING ILD





To better understand the changes that occur to lung tissue with IPF, let's compare the lungs to a sponge.



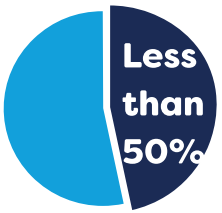


Lung with healthy tissue is like a wet sponge. It can be easily compressed and quickly returns to its orig-inal shape. A wet sponge contracts and expands smoothly, like healthy lungs, i.e. breathing is not limited.

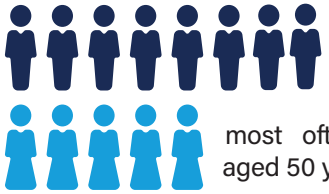
The scarred and rigid tissue typical of ILD-damaged lungs is more like a dry sponge: It is very difficult to compress and very inflexible. The same phenomenon occurs in IPF-damaged lungs: they have trouble expanding due to the scar tissue, making breathing more difficult.

Overview of the disease in Canada

Interstitial lung disease (ILD) is a broad group of more than 200 diseases that can cause irreversible scarring of the lungs, which negatively impacts their function.



It is estimated that just under **50% of patients with ILD have a progressive fibrosing form of the disease.**



That's nearly 25,000 Canadians. ILD mainly affects adults and is most often diagnosed in men aged 50 years or older.

However, it can affect people of all genders and ages. In the majority of cases, people with the disease often receive a late diagnosis, i.e. after several visits to the doctor, or no diagnosis at all. It is also common for them to be diagnosed with asthma, COPD, emphysema or heart disease prior to receiving a diagnosis of progressive fibrosing ILD, often called "pulmonary fibrosis."

Possible signs and symptoms

As its name implies, progressive fibrosing interstitial lung disease is a disease that progresses and worsens over time. Signs and symptoms may appear over several months or even years.

The symptoms associated with progressive fibrosing ILD can vary from one person to another.

- Trouble breathing (shortness of breath)
- Dry cough
- Fatigue
- Loss of appetite
- Weight loss
- Enlargement of the fingertips, or clubbing (with IPF)

Be attentive to sudden changes to your symptoms. Your symptoms, including shortness of breath and cough, may suddenly worsen over a period of days or weeks. You may think you have a cold or the flu. However, it is important to contact your healthcare team immediately as this may be an acute exacerbation, a sudden worsening of the disease.

An acute exacerbation may be due to an underlying problem, but in many cases no specific cause can be identified. Whether the cause is known or not, the symptoms, the severity and the treatment remain the same.

Not all people with IPF experience acute exacerbation, but it is important to recognize the symptoms, which may include:

- Greater difficulty breathing that comes on suddenly Breathing taking more effort than usual and no improvement in your condition
- A cough getting worse
- Fever or flu-like symptoms (such as aches and pains)

To better understand what happens during an exacerbation, let's compare IPF to the embers of a campfire. During exacerbation, these embers ignite violently, causing a sudden, raging fire. Just as it is important to quickly put out the flames of a fire, it is important for people with IPF to have an action plan they can quickly set in motion to manage the symptoms of the exacerbation.

Baseline condition

Exacerbation

What to expect with progressive fibrosing ILD ?

Progressive fibrosing ILD is a chronic, progressive disease, which means it can get worse over time. How progressive fibrosing ILD will present can differ from person to person and may vary depending on the initial diagnosis, such as hypersensitivity pneumonitis or COPD associated with rheumatoid arthritis.

Some people with progressive fibrosing ILD remain fairly stable or their state may slowly deteriorate over time. A small number of people will have symptoms that worsen rapidly following diagnosis.

The diagram illustrates several possible trajectories for someone living with idiopathic pulmonary fibrosis (IPF), a type of progressive fibrosing ILD, ranging from a disease that remains fairly stable or slowly worsens over time to a disease that progresses rapidly.

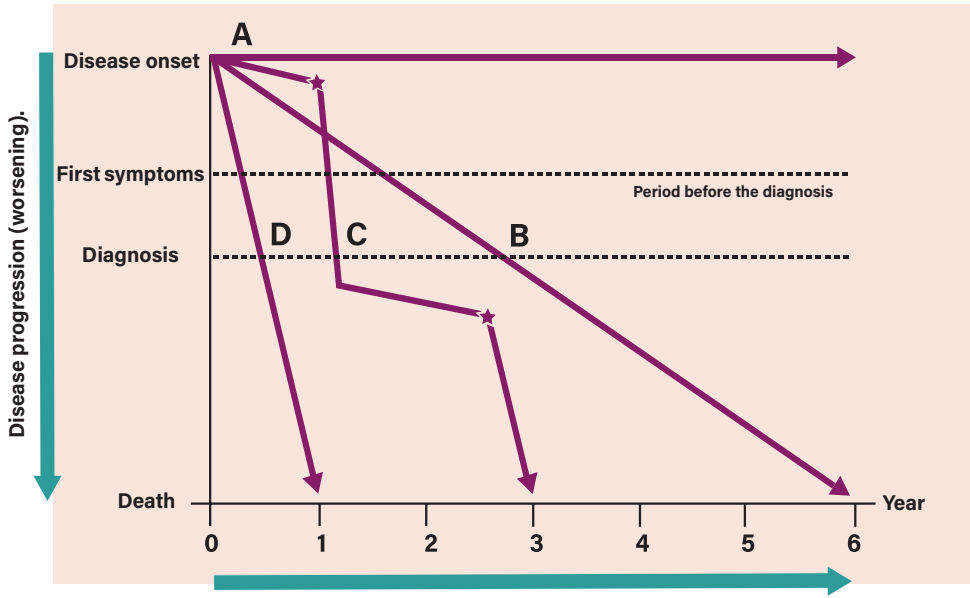
The natural progression of IPF, a type of progressive fibrosing ILD

A. Stable disease.

B. Gradual progression.

C. Stable disease with sudden worsening due to acute exacerbations(★).

D. Rapid progression.



Adapted by : Raghu G, & al. Am J Respir Crit Care Med2011;183:677-824.

Cough management

Coughing is a protective physiological reflex triggered by irritated airways. In people with IPF, the cough is dry, i.e. no secretions. The cause of cough in progressive fibrosing ILD patients remains unknown to this day.

Triggers

Several factors can trigger or aggravate a cough. These can vary from one person to another. Although it is not always easy, it is important to identify the things that cause the onset or worsening of coughs and avoid them as much as possible.

Respiratory infections (cold, flu, etc.)

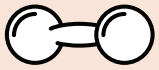
Gastroesophageal reflux disease

Irritating products

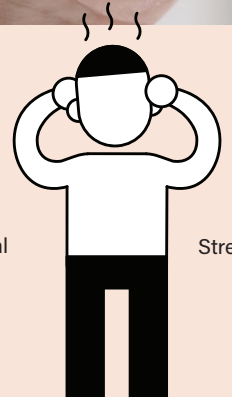
Strong odours (fragrances and perfumes)

Tobacco smoke

Sudden changes in temperature (cold air and humidity)



Unadapted physical exercise



Stress and anxiety

Impacts on your daily life

Coughing can affect your daily life in a major way:

- Sleep disturbance
- Rough voice
- Chest pain
- Difficulty performing certain daily activities

Coughing can also affect your social or work life. Being unable to control it, you may feel embarrassed, isolated and self-conscious. In order to break the isolation, do not hesitate to talk to the people around you.

› Cough relief

To help you better manage your cough, it is important to adopt good habits. Avoid triggers, stay well hydrated and talk to your doctor to rule out underlying causes that may be making you cough.

› Avoid self-medicating

Conventional cough suppressants in syrup form and cough drops have not been shown to be useful in treating cough in people with IPF and should not be used. You should also avoid using essential oils, which can irritate the respiratory tract.

› Opt for natural remedies

Honey with herbal extracts can help relieve throat irritation and dryness, as well as protect the mucous membranes. A warm drink with honey or candies that contain glycerin can also help relieve irritation. Even though these are natural remedies, it is important to check with your doctor or pharmacist to make sure they are right for you.

If you have a nighttime cough, using a humidifier may help relieve your symptoms.

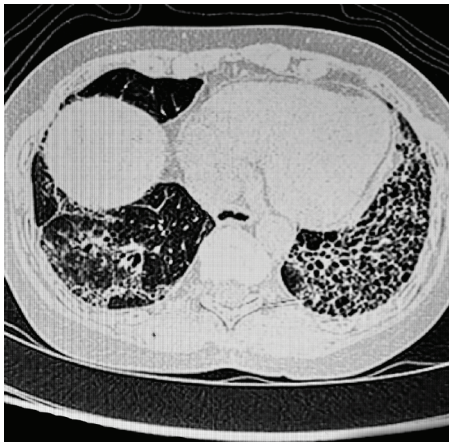
Do not hesitate to ask your doctor or pharmacist for advice to help you manage your cough.

ILD diagnosis and monitoring

High-resolution computed tomography (HR-CT)

An important assessment tool used in IPF diagnosis and monitoring. HR-CT is a more detailed type of imaging that scans the chest and produces a 3D visual reconstruction.

The term "honeycomb" is used to describe the characteristic appearance of alveoli (air sacs) damaged by ILD.



Lung function tests

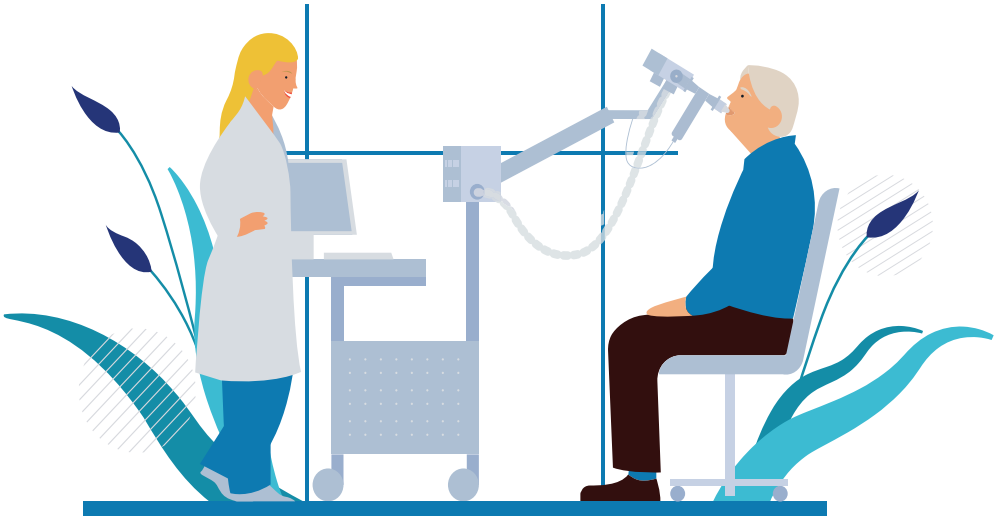
Lung function tests are often performed and can tip off your doctor that you may have developed pulmonary fibrosis. These tests will also be used to measure the progression of lung damage.

Forced Vital Capacity (FVC)

- This is a measure of the size of your lungs, calculated from the amount of air you can forcibly exhale (quickly and for as long as possible) after fully inhaling.

Carbon monoxide diffusing capacity (DL_{CO})

- DL_{CO} measures the ability of the alveoli to diffuse carbon dioxide (CO_2) into the lungs and provides insight into the ability of the lungs to transport oxygen from the alveoli into the blood.



Lung biopsy

If a diagnosis of progressive fibrosing ILD cannot be clearly established based on the HR-CT, a biopsy (a very small sample of lung tissue) may be taken for laboratory analysis. Therefore, a lung biopsy is not performed on every patient with this diagnosis.

Six-minute walk test

The six-minute walk test aims to measure your tolerance to exercise, but also to highlight and quantify the decrease in oxygen levels during exertion.

Several metrics are assessed before starting the test, including your blood pressure, shortness of breath, fatigue, heart rate and saturation level.

You are then asked to walk the longest distance possible in six minutes. During this test, your distance travelled, your stops to rest, your heart rate and your saturation level are observed.

Once the six minutes are up, the distance you covered, your shortness of breath, fatigue, heart rate and saturation level are reassessed. The time required for all these values to return to their initial level (that observed before the test) is also assessed.

Impact of progressive fibrosing ILD on daily life

Progressive fibrosing ILD causes a deterioration in lung function and increased shortness of breath. On a day-to-day basis, this translates into fatigue, decreased physical fitness and ability to perform daily activities, as well as decreased quality of life.

Continuous monitoring: knowing your body

You are your own alarm system! Understanding how IPF affects you will help you better manage your symptoms, know what to expect and take action when you sense a change in your condition. That means that you play an important role in managing your symptoms. These can be positive, indicating an improvement in your health, or negative. If negative, you will probably want to talk to your practitioner.

What can I do?

- **Attend** all your medical appointments.
- **Keep a journal** and record how you feel every day. For example, you can add a quick note in the morning, at lunch and at night in a journal or a notebook. Bring this journal to all appointments with your healthcare professional.
- **Determine** with your practitioner (doctor or nurse) when you should contact them outside of your regular appointments.
- **Develop a plan** to follow if you experience an acute exacerbation.
- **Know the symptoms of a lung infection** (fever, chest pain, coloured sputum, increased coughing and shortness of breath, etc.) and consult your contact person without delay.

Changes to your habits, whether big or small, can also play a role in managing the disease and your quality of life.

- If you smoke, quit the habit, and avoid places with smoke, dust or heavy air pollution whenever possible.
- Try to stay active to maintain your lung health. Simple, low-impact exercises will help. The Quebec Lung Association can provide you with a complete guide on that subject. You can view it at **poumonquebec.ca/en** or order your free copy by calling **1-888-POUMON-9**. It is important to get your doctor's approval before starting a physical activity program.
- If you have gastroesophageal reflux disease, talk to your practitioner. A healthy diet will help reduce these symptoms and increase your energy level.
- Try to avoid getting lung infections:
  - Get an annual flu shot and, if possible, a pneumococcal vaccine.
  - Wash your hands regularly with warm water and soap, or use an antiseptic hand sanitizer.
  - Avoid contact with people with active infections, such as coughs, colds, flu or pneumonia.
  - Stay positive and be creative: think of other ways to continue doing the things you love.
- Join support groups or a peer-to-peer support system to help you cope with your feelings about IPF and to get practical advice from others who are going through the same things. Do not hesitate to join the **UnaUn.ca** platform (in French only).

Emotional impact of the disease

Receiving the diagnosis, the severity of the disease and the vast range of IPF symptoms can have an impact on your emotional health. This is quite normal, considering the upheaval this causes in your daily life. The gradual loss of autonomy and the prognosis can lead to social withdrawal and sometimes even depression.

It is important to talk to your medical team about these feelings so they can support you and direct you to available resources. Psychological support is often recommended. Various services, such as UnaUn.ca, a free peer-to-peer program run by the Quebec Lung Association, allow people newly diagnosed with the disease to talk privately with other people living with the disease or with family caregivers. Participating in art workshops or a book club is also a good way to reduce isolation and maintain a social life.

In addition to the consequences on activities, coughing alone can be a problem when around other people. Not being able to control it can cause embarrassment and enough discomfort to lead to isolation. This is a common problem and affects the quality of the affected person's social life.

For their loved ones, the feeling of helplessness and distress is also painful. The support of family and friends (caregivers) is essential to reassure the person affected and provide the best possible support. However, this is a demanding role that can lead to burnout. It is essential that caregivers get rest periods to allow them to take care of themselves.

My progressive fibrosing ILD

Knowing your baseline condition, especially if you live alone, can help you better assess the worsening of some of the symptoms. It is recommended that you complete the tables below when you are in your usual state, not in exacerbation. It can be modified over time depending on the evolution of the disease.

MY COUGH		
	Type of cough **D :** Dry **W :** Wet **M :** Mixed (dry and wet)	**Frequency** **0 :**None **+ :** Light **++ :** Medium **+++ :** Intense
Upon waking		
At lunch		
At bedtime		

MY SHORTNESS OF BREATH				
Use the following scale to rate your shortness of breath:				
1 : almost none	2 : light	3 : medium	4 : intense	5 : completely out of breath

Walking around the house: _____	Doing laundry: _____
Talking while sitting: _____	Talking while moving: _____
Reading or watching TV: _____	Getting dressed: _____
Climbing stairs with 8 to 10 steps: _____	Taking a shower or a bath: _____

MY LEVEL OF ACTIVITY

Check the statement that corresponds to your activity level

☐ I am active and able to do the same activities as before the disease.	☐ I am restricted in my physical activities, but I can get around and do light daily activities (e.g. simple tasks around the house).	☐ I am able to get around and take care of myself, but unable to perform activities.	☐ I have very limited capacity and spend most of my days sitting in a chair or lying in bed.	☐ I am completely disabled, I can't take care of myself and I spend the entire day sitting in a chair or lying in bed.

Preparing for a visit to the doctor

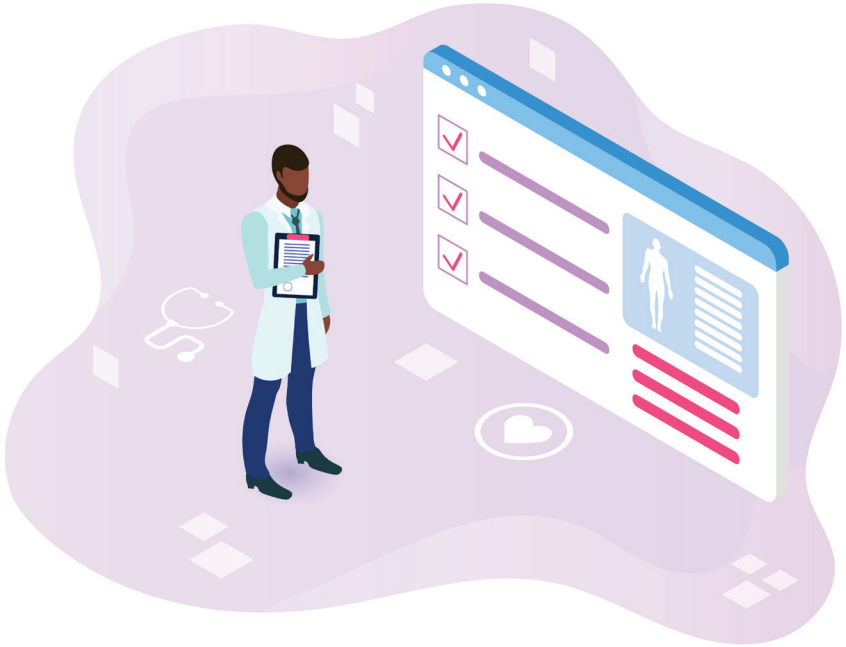
Visits to the doctor can be rather brief. For this reason, it can be helpful to write down the questions you want to ask in advance.

Here are some examples of questions you can ask your doctor:

- ☐ What stage is my disease in?
- ☐ What can I expect from this disease?
- ☐ What are my treatment options?
- ☐ When should oxygen be used?
- ☐ What changes to my symptoms should I watch for?
- ☐ What should I do if my symptoms get worse?
- ☐ Who should I contact if my symptoms get worse?
- ☐ Why are my symptoms getting worse?
- ☐ Is a lung transplant a possibility?
- ☐ How often will follow-ups take place?
- ☐ What exercises can I do and which should I avoid?
- ☐ Does my condition allow me to travel?
- ☐ How will the disease affect me over the next year?
- ☐ Are my children at greater risk of developing IPF?
- ☐ What are the side effects of the medications?
- ☐ What can I do to manage the side effects of the medications?
- ☐ Will I be able to continue working?

To help you ask the right questions and remember the details of the answers, it can be helpful to have a friend or family member with you when you meet with the doctor.

Living with progressive fibrosing ILD: Your care plan



First, a specific diagnosis of progressive fibrosing ILD must be made before a personalized care plan can be drawn up. Your care team will discuss the elements of your care plan with you and will regularly monitor your condition and symptoms.

NON-DRUG TREATMENTS

Your care plan may include non-drug treatments such as:

Smoking cessation

If you smoke, your doctor will definitely urge you to quit. To help you succeed, he or she will likely prescribe nicotine replacement products such as patches, gum or lozenges. Moral support is also available through the Quebec Lung Association or through smoking cessation centres (contact your local CLSC for more information).

Pulmonary rehabilitation

Pulmonary rehabilitation includes a number of different therapies and programs to support physical and emotional health. It can help alleviate symptoms and improve activity levels. Its benefits may include:

- Improved physical fitness, which can help you stay active;
- Improved breathing and reduced shortness of breath;
- Reduced stress and feelings of anxiety and depression;
- Improved nutrition;
- Improved health-related quality of life.

Symptom management (palliative care)

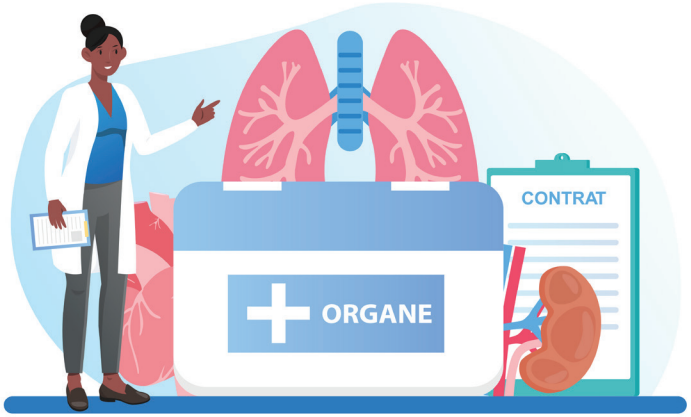
The goal of palliative care is to reduce symptoms of IPF, such as shortness of breath (dyspnea), cough and fatigue, and to make you comfortable. Palliative care is provided as part of your IPF treatment plan. It may involve medications, or not, and is intended to improve quality of life by helping to manage symptoms while providing additional support.

Lung transplant

A lung transplant is an option for some people with IPF and can extend life expectancy and quality of life. Your doctor will be able to tell you if you are eligible for a lung transplant, based on your overall health. Unfortunately, this option is not a cure for the disease and is not suitable for all patients due to the many complications it can cause. In addition, due to a lack of organ donors, the list of people waiting for a transplant is very long.

DRUG TREATMENTS

Since it is an irreversible progressive disease, drug treatments aim to slow its progression, as do smoking cessation and symptom management.



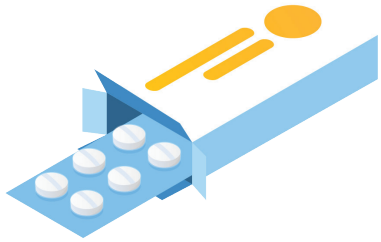
Oxygen therapy

In Quebec, oxygen is classified as a medical gas and is regulated as a drug. A prescription from a doctor is required to obtain it. In addition, oxygen is usually at the user's expense, as it is not covered by the RAMQ.

To find out if oxygen therapy could help you, a blood test (usually an arterial puncture) must be performed to measure the level of oxygen in your blood. If the level is low, giving the lungs supplemental oxygen via a tank or a concentrator (a device that takes air from the room and increases the oxygen content) will raise the oxygen level in the blood and reduce shortness of breath. Your doctor will determine how much oxygen you need, how often you need it, and what type of device is best for you.

Anti-fibrotic drugs

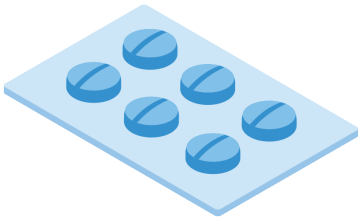
To date, after several years of research, two drugs, pirfenidone (Esbriet®) and nintedanib (OFEV®) have proven therapeutic efficacy in slowing the progression of idiopathic pulmonary fibrosis. However, only nintedanib is indicated for progressive fibrosing ILD. It helps to slow the progression of the disease while also reducing the risk of acute exacerbation.



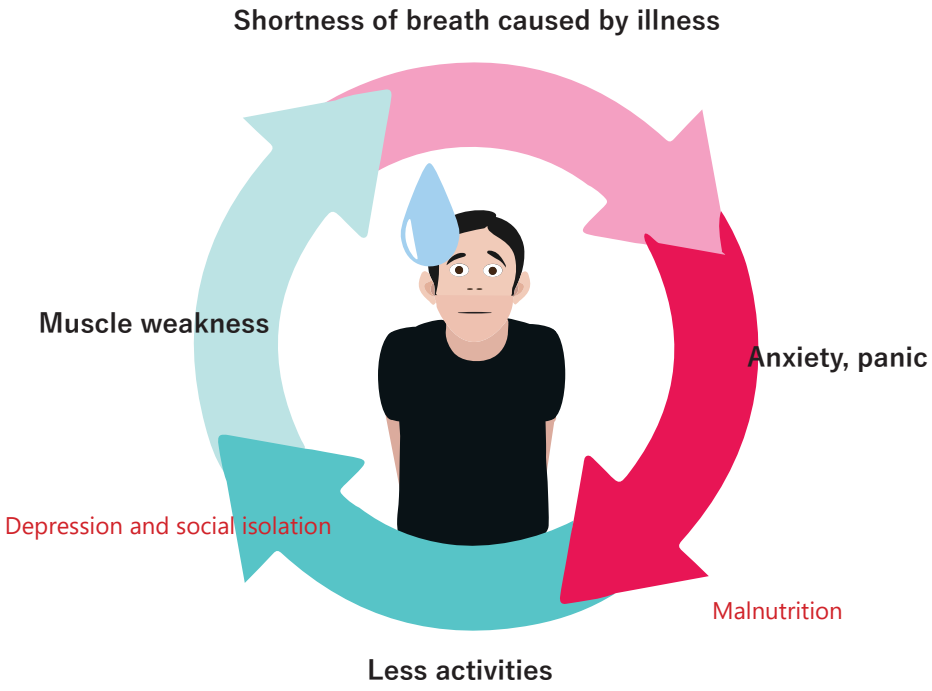
Since these are exceptional drugs, specific criteria established by the RAMQ must be met in order to benefit from them.

Opioids

In rarer cases with very frequent coughing and severe shortness of breath, your doctor may prescribe opioids to reduce your symptoms and increase your comfort.



Living with progressive fibrosing ILD: Adapt your daily life



Progressive fibrosing ILD

Shortness of breath can become very disabling. For this reason, promptly managing this symptom is essential.

The image above represents the evolution of the disease in a person who has stopped being physically active.

People who experienced increased shortness of breath tend to decrease their activities. This decrease will lead to physical deconditioning and muscle weakness in the medium term. The deconditioning will result in increased breathlessness, which will contribute to the development of exercise anxiety.

Depression and social isolation are often associated with IPF, as people with IPF restrict themselves from activities for fear of being tired or out of breath. By exercising regularly, it is possible to escape this vicious cycle.

Managing shortness of breath with appropriate techniques will prevent anxiety and muscle atrophy. Bringing the vicious cycle of breathlessness under control will greatly improve your quality of life and stabilize the progression of the disease.

Be physically active on a regular basis

Regular, moderate physical activity will strengthen your muscles and keep your body as functional as possible, helping you manage your shortness of breath. Exercise will also have a positive impact on your morale.

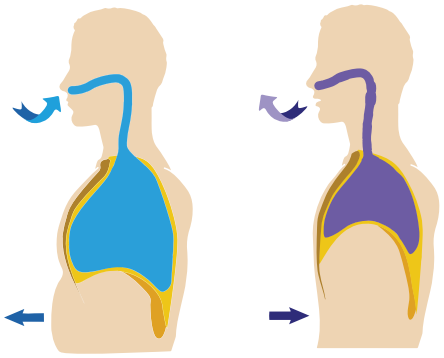
When practiced daily, physical activity will help your body maintain the ability to oxygenate itself, and sometimes even improve it, thanks to exercises adapted to your needs.

Staying active is important, but so is respecting your limits. Learn to recognize your limits and take time off when you need it.

For more details on exercise, see our Guide d'enseignement et de réadaptation pulmonaire (pulmonary education and rehabilitation guide, in French only), available for download on our website. Also, talk to your healthcare provider about joining a pulmonary rehabilitation program.

Manage your anxiety

To optimize the oxygenation of your lungs, it is important to limit stress as much as possible. Diaphragmatic breathing can help you relax and loosen the muscles in your chest. This breathing technique promotes slow, deep breathing that allows for better control of anxiety.



1. Get comfortable.
2. Place one hand on your belly to monitor your breathing.
3. Breathe in through your nose while inflating your stomach.
4. Purse your lips and exhale while pulling in your stomach.

If you feel dizzy, stop diaphragmatic breathing and return to normal breathing. We suggest that you familiarize yourself with this breathing technique by practicing it when you are at rest and do not feel out of breath.

Get help at home

As the disease progresses, you may find it difficult to perform daily tasks. You can ask for help at home by contacting your local CLSC. You may be able to get help with everyday tasks such as bathing, getting dressed or feeding yourself. It is also possible to adapt your home, for example by reorganizing certain rooms in your house to facilitate your movements.

Managing the side effects of drug treatments

Like many medications, anti-fibrotic drugs can have side effects. However, there are some things you can do for prevention or relief.

Diarrhea

- It is recommended that you drink at least 1.5 liters of fluid per day. Instead of just drinking water, you can opt for magnesium-rich water, herbal teas or broth (chicken or vegetable, for example). Milk and coffee should be avoided.
- Opt for a varied diet, but include starchy foods that are low in dietary fibre, such as pasta and rice.
- Avoid eating raw fruits and vegetables. It is preferable to consume them cooked, in a soup, for example. Carrots, beets, zucchini, pears and bananas are excellent choices.
- Take the anti-fibrotic treatment with a meal.

Nausea and vomiting

- Choose less fragrant foods. Food is often less fragrant when eaten cold or at room temperature.
- Avoid heavy, hard-to-digest foods, such as fried foods.
- Eat slowly and drink before and after your meal, rather than during it.

Decreased appetite and loss of appetite

- If you are craving a certain type of food, go ahead and have some!
- Break up the amount of food you should eat into smaller portions throughout the day.
- Make sure you have a pleasant atmosphere for the meal and, if possible, share the meal with other people.

Photosensitivity (abnormal reaction of the skin to the sun)

- Avoid exposure to strong sunlight, such as mid-day and afternoon light.
- Wear light clothing that covers your body. Wearing a long-sleeved shirt and a wide-brimmed hat to protect the face and neck is recommended.
- Use a sunscreen with 50+ UVA and UVB protection, and remember to apply it frequently.
- Remember that sunrays penetrate car windows, so do not forget to protect yourself.

Follow your dreams

Travelling with IPF

Having progressive fibrosing interstitial lung disease does not mean you have to stop travelling. Instead, it is important to continue doing the things you enjoy, such as taking vacations or visiting family and friends. However, to limit the impact that travel can have on your illness, it is important to be well-prepared. Do not hesitate to discuss your travel plans with your healthcare team. They will be able to advise you on the type of destination to consider.

› Choose the destination

People with IPF may be more affected when travelling to certain areas, notably due to altitude, climate or air quality.

› Altitude

There is less oxygen available at high altitudes, which makes breathing more difficult. Because of these conditions, high-altitude travel is normally not recommended for people with IPF. If you must travel to a high-altitude destination, you may need additional oxygen or an adjustment to your current treatment.

› Climate

Very hot or very cold climates can make it harder for you to breathe, which can cause symptoms like coughing or shortness of breath. Before your trip, check what the climate is like at your destination. Depending on the season, pollen can also affect your breathing.

› Type of terrain

If you plan to do any recreational activities during your trip, ask about the type of terrain these activities will take place on. Moving across sloping or uneven terrain will require more effort, which can increase your shortness of breath.

› Air quality

Air quality can make it harder for you to breathe. Check what the air quality is like at the destinations you plan to visit.

Getting around

Regardless of the mode of transportation used, it is important to consider your health condition and plan accordingly. To facilitate your travels, ask your doctor to provide you with a letter stating that you are fit to travel.

› Airplane

Air travel is usually authorized for people with IPF, but requires the approval of your medical team, who will assess your condition, the duration of the flight and the need to adjust your oxygen intake. If you choose this mode of transportation, you will need to plan ahead, which includes consulting with your care team.

› Oxygen

It is possible to travel even when using oxygen. In this case, it will be important to contact your oxygen provider as well as the transport company to plan your trip. Most transport companies allow passengers to use oxygen on board, but others may require special authorization. Remember to ask your doctor for a copy of your oxygen prescription and plan to bring spare accessories. If necessary, you can apply for special needs assistance from the transport company.

› Wheelchair

If you use a wheelchair to get around, check with the transport company to see if they have a wheelchair ramp or if they provide assistance to help you get in and out of the vehicle.

Medication

There are certain rules to follow when travelling with medication. Bring enough medication for the duration of your stay, and even a little more in case of unforeseen circumstances.

› Storage

To avoid confusion, your medications must be transported in their original container. This will make it easier for you to pass through security, but it will also allow you to inform medical personnel more quickly of the medications you are taking in case of an emergency.

› Transport

Keep your medication with you during transport and never check it with your luggage. Some medications are temperature-sensitive, and your luggage could arrive late at your destination or simply be lost.

› Prescriptions

Do not forget to bring your prescriptions with you. You may need to refill a medication during your trip. Also, consider having your prescriptions translated into the language used at your destination. Bring your doctor's contact information, a list of your medications, and any other relevant information regarding your medical condition.

› Schedule

If you have to take your medication on a strict schedule, remember that you may be affected by jet lag. Before you leave, discuss that matter with your care team so that you can plan according to your destination's time zone.

Vaccination

Preventing respiratory infections through vaccination is very important when you have a chronic lung disease like IPF. Several months before your departure, discuss the vaccines required for your destination and the conditions of your stay with your doctor. It is important to plan ahead to ensure that the vaccines you receive will give you adequate protection.

Insurance

Before leaving on a trip, it is very important to validate your travel insurance coverage. Make sure that your insurance covers the costs related to:

- Visits to the doctor;
- Emergency medication;
- Emergency dental care;
- Emergency transportation;
- Necessary cash advances;
- Repatriation;
- Accompaniment by a medical care team;
- Cancellation or interruption of the trip.

DID YOU KNOW THAT

the Quebec Lung Association (QLA) offers support groups for people diagnosed with lung diseases? One of them is entirely dedicated to IPF. If you need information, we also have a toll-free number you can call from Monday through Friday. Furthermore, since June 2021, we offer a peer-to-peer support platform that matches two people with similar realities so they can have someone to share their experience with. Finally, the QLA offers a complete pulmonary rehabilitation program, both in person and virtually. It is the first centre of its kind to be established in a community setting.

Information line
1-888-POUMON-9 ext. 232
info@poumonquebec.ca
Support groups
1-888-POUMON-9 ext. 230
Un à Un Peer-to-Peer Matching Platform
Unaun.ca

Association pulmonaire du Québec