

LIVING WELL WITH PULMONARY FIBROSIS BY RESPIPLUS™

A Learning Tool for Patients and Their Families



GET MOVING... BREATHE EASY WITH PULMONARY FIBROSIS

This guide belongs to:

Healthcare Professional:

Institution:

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THE SKILLS YOU NEED TO MANAGE YOUR PULMONARY FIBROSIS

Pulmonary Fibrosis (also known as interstitial lung disease) is a disease that can affect every part of your life. As the disease progresses, so will its impact on your life and your daily activities. The exacerbations of the disease, or period of worsening symptoms can greatly affect your quality of life.

There are things that you can do to help you live well with this disease. This module is part of “Living well with Pulmonary Fibrosis”, a self-management program, created for those affected by the disease by medical experts in collaboration with patients.

HOW CAN THIS PROGRAM HELP ME?

With “Living well with Pulmonary Fibrosis” you will learn skills to adopt healthy new lifestyle behaviours. This module is your guide. It was designed for you to be able to review at your own pace. Take it from the top or skip to the topics that are most meaningful to you. Share it with people close to you so that they can understand what you are going through.

We wish you well as you go through this program. Do not hesitate to discuss whatever thoughts and feelings you have with your resource person, professionals in your healthcare team and your physician.

On behalf of Team RESPIPLUS



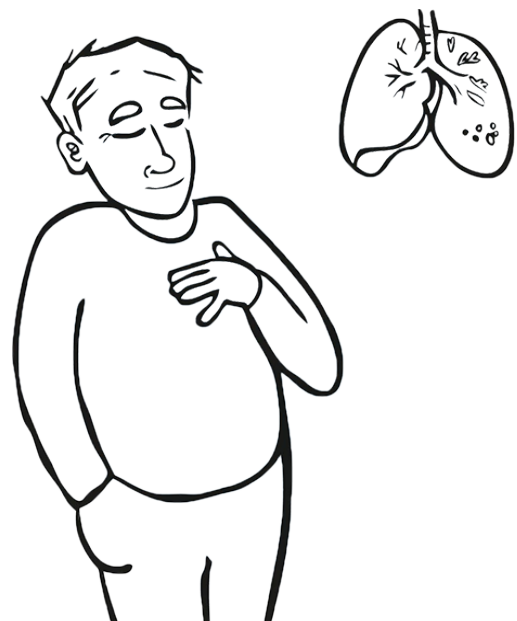
WELCOME TO THE MODULE "GET MOVING BREATHE EASY WITH PULMONARY FIBROSIS"

Identify, with the help of your resource person, the subjects on which you need additional information to better manage your Pulmonary Fibrosis. Check off each subject that interests you or is important for you at this time.

Get Moving... Breathe Easy with Pulmonary Fibrosis

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Living well with Pulmonary Fibrosis means adopting and maintaining healthy life habits and behaviours in order to improve your quality of life.



GET MOVING...

BREATHE EASY

WITH

PULMONARY

FIBROSIS

GET MOVING... BREATHE EASY

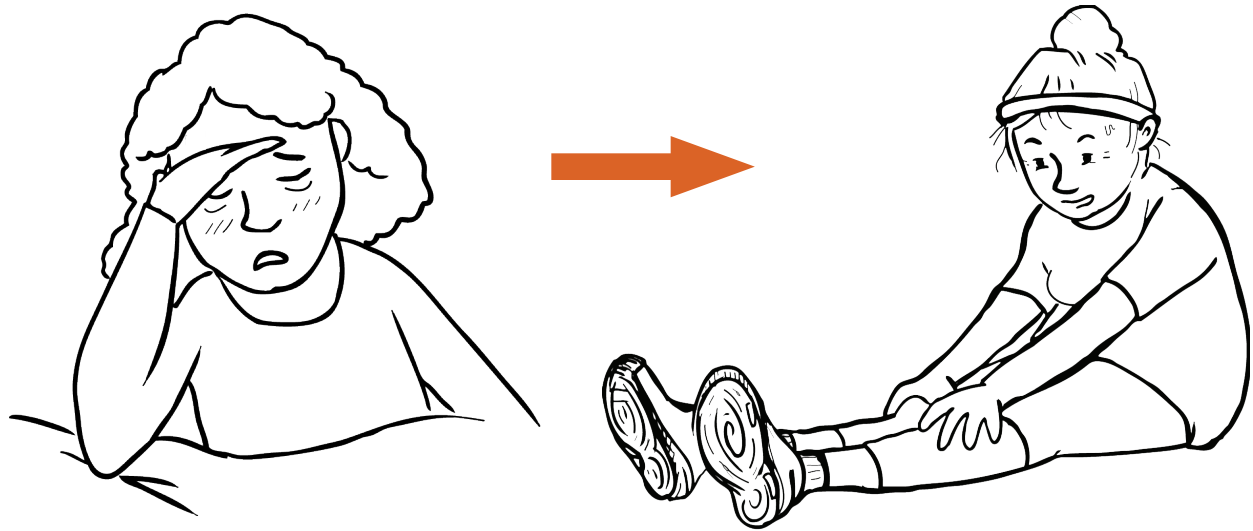
Despite constant breathlessness, it is very important for people with pulmonary fibrosis or any chronic respiratory disease to keep active; otherwise they gradually lose autonomy and quality of life because of persistent fatigue and reduced tolerance to effort.

Living well with pulmonary fibrosis means getting moving to breathe better.

The objective of this module is to motivate people with pulmonary fibrosis and their family to increase their level of daily physical activity on a long-term basis.



WHY MUST WE INCREASE OUR LEVEL OF PHYSICAL ACTIVITY?



BEING ACTIVE HELPS YOU:

- **Increase your strength and your tolerance to effort:**
“I move more. I started with housework; I am now able to do the cleaning, the laundry and my meals.”
- **Better control your anxiety:**
“Feeling less breathless and being able to accomplish more makes me less anxious.”
- **Increase your confidence in your own abilities:**
“I have more self-confidence, I know that I can accomplish more and in the end I reap the benefits.”
- **Improve your quality of life:**
“My quality of life has improved because I am in better shape; I can accomplish more and I feel more useful.”

RECOMMENDATIONS:

Be active!

It is recommended that you do 30 minutes of physical activity per day.

DO SOME PHYSICAL ACTIVITY EVERY DAY:

- **Walking indoors or outdoors**
- **Pedaling a stationary bicycle with low to moderate resistance**
- **Walking up stairs, taking time to rest when needed (3 or 4 steps at a time)**
- **Participating in leisure activities (yoga, tai chi, ballroom dancing, bowling, shopping, etc.)**
- **Engaging in daily life activities (housework, laundry, gardening, grocery shopping, walking to the convenience store instead of driving, preparing meals, etc.)**

Time spent on physical activities can be spread out according to what is convenient for you: three 10-minute periods are just as good as a single 30-minute session.

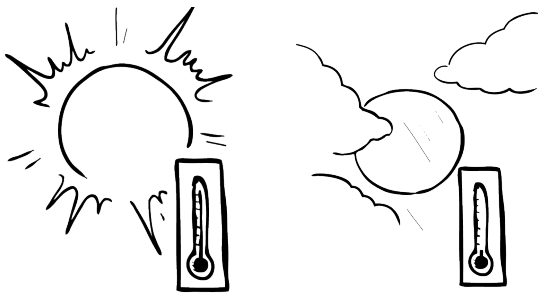
AIM TO MAINTAIN YOUR LEVEL OF PHYSICAL ACTIVITY FOR THE LONG TERM

- If you enjoy outdoor activities, you should plan and adapt an activity for each season. Such as indoor walking in the winter, gardening in the spring, cycling in the summer and hiking in the fall.
- Consider some indoor activities as well, which have the advantage of not depending on weather conditions (gym, stationary bicycle, swimming).
- Your level of performance can vary over time; what is most important is to be regularly active.



REMEMBER:

- Set aside moments of the day when you feel well to engage in physical activity.
- Avoid physical activity immediately after eating, or at night before going to bed.
- Wear comfortable clothes and appropriate shoes.



- Avoid environmental factors likely to increase your symptoms (e.g. extreme heat or cold, high humidity, smog or strong winds).

- Invite your friends and family to join you in physical activities.
- Having oxygen therapy does not mean you cannot exercise. It is recommended for all people with pulmonary fibrosis to be involved in physical activity. If you are on oxygen, please refer to our module *"Integrating Oxygen therapy into your life"*.



HOW CAN YOU TELL IF THE INTENSITY OF YOUR PHYSICAL ACTIVITY IS ADEQUATE?

Use the **Scale of perceived exertion** below. Looking at the scale, evaluate your level of breathlessness between 0-10. Then again, using the same scale, evaluate the intensity of your muscular fatigue.

SCALE OF PERCEIVED EXERTION¹

Intensity of the sensation (breathlessness, fatigue)



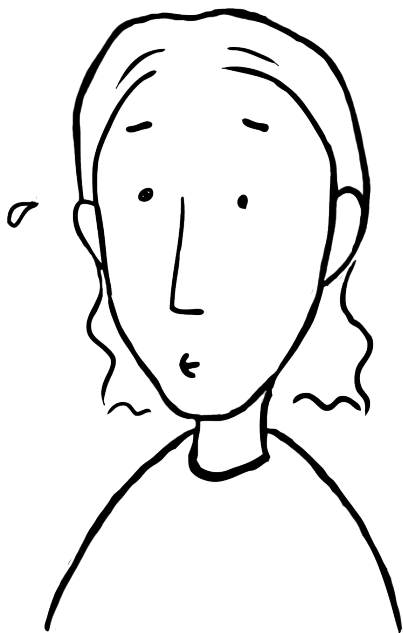
Start at a comfortable pace. It is normal to experience a light degree of breathlessness. It is recommended that you perform physical activity at a level of breathlessness and fatigue between 3 and 6 on a scale of 10.

1. Borg, G. *Perceived exertion and pain scales*. Human Kinetics, Champaign (1998).

WHAT ARE THE NORMAL AND ABNORMAL SYMPTOMS THAT CAN BE PRESENT DURING PHYSICAL ACTIVITY?

NORMAL SYMPTOMS

- Light to moderate breathlessness and/or mild cough
- Sweating
- Feeling of heat or fatigue in the legs
- Light muscular or joint pain



ABNORMAL SYMPTOMS

If you present these symptoms, you should reduce or stop physical activity:

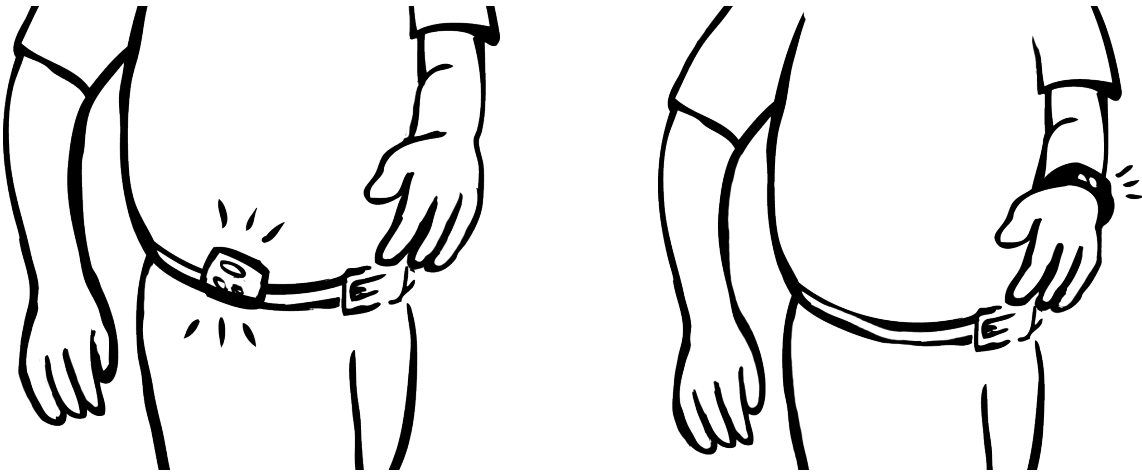
- Chest pain
- Intense joint pain
- Dizziness or vertigo
- Heart palpitations
- Severe and prolonged respiratory problems
- Severe and persistent coughing fits
- Severe headache

If you present any of these symptoms, you should stop physical activity temporarily and contact your doctor and/or resource person.

HERE ARE A FEW WAYS TO HELP YOU INCREASE YOUR LEVEL OF PHYSICAL ACTIVITY AND MONITOR YOUR PROGRESS

A) USE A PEDOMETER

The pedometer is a movement detector that counts every step you take. There are many types available. Some are worn on your wrist like a watch and others can be clipped on your waistband. Many new smart-phones even count your steps while in your pocket. This device will encourage you to go a bit further every day. Using it will allow you to challenge yourself and observe your progress.



3-STEP PEDOMETER TECHNIQUE

1. In order to determine the average number of steps you take every day, note the number of steps you take over 3 consecutive days (making sure to include 1 weekend day).
2. Your first objective will be to add 1000 steps to your daily average. Maintain this level over a one-month period.
3. If you reach your goal, add another 1000 steps and maintain this for one month. Keep increasing your objective in this way until you have reached 5000 to 6000 steps per day. If your condition allows it, you can keep increasing up to 10,000 steps per day.

Note: There are many different types of pedometers on the market. Inquire carefully before making your purchase.

HERE ARE A FEW WAYS TO HELP YOU INCREASE YOUR LEVEL OF PHYSICAL ACTIVITY AND MONITOR YOUR PROGRESS

REGISTER AT A GYM OR COMMUNITY CENTRE

Gyms and community centres offer a variety of programs that could be suitable for you. Maybe you would like to engage in physical activity with friends or in a group. Inquire about programs available in your neighbourhood. An individualized evaluation by a professional from these centers could be desirable. Please remember to clearly describe your medical conditions to a trainer before the start of the program.



HERE ARE A FEW WAYS TO HELP YOU INCREASE YOUR LEVEL OF PHYSICAL ACTIVITY AND MONITOR YOUR PROGRESS

C) PARTICIPATE IN A PULMONARY REHABILITATION PROGRAM

Pulmonary rehabilitation is a structured and supervised exercise program for people with a chronic pulmonary disease.

- If you are limited in your daily activities and you need support to start an exercise program, speak to your doctor or healthcare professional to be referred to a pulmonary rehabilitation specialist.
- Inquire about existing programs by consulting these websites:

www.pq.lung.ca, the Québec Lung Association

www.lung.ca, the Canadian Lung Association

www.pulmonaryfibrosis.org, the Pulmonary Fibrosis Foundation

Further reading can be done on these websites concerning this topic

On a scale of 1 to 10, circle the number that best represents your ability to increase your level of physical activity on a regular, long-term basis.

1 2 3 4 5 6 7 8 9 10

not at all confident very confident

1 2 3 4 5 6 7 8 9 10

not at all confident very confident

1 2 3 4 5 6 7 8 9 10

not at all confident very confident

MY COMMITMENT TO PHYSICAL ACTIVITY

If you feel confident, do not hesitate to engage in physical activities that are of interest to you, on a daily basis. Make a commitment now by completing and signing the following contract:

Learning contract	
1. Identify at least 3 physical activities you would like to engage in:	
Physical activity:	
At which time of day?	
Min/day?	Times/week:
Physical activity:	
At which time of day?	
Min/day?	Times/week:
Physical activity:	
At which time of day?	
Min/day?	Times/week:
2. If I use a pedometer, I will increase the number of steps I take each day by _____ and will maintain this level for the next month.	
3. Here is my plan for maintaining my physical activities in the long-term:	

Date:	Your signature:
Signature of a friend or family member:	

GET MOVING... IN SUMMARY

You may find yourself unable to increase your level of physical activity despite having used the recommendations made in this module. If that is the case, speak to your doctor or other resource persons to discuss the things that keep you from being more active.

TO SUMMARIZE:

- **Be physically active on a daily basis.**
- **By being more active, you will have better control of your shortness of breath, be able to accomplish more, and increase your quality of life.**

There are other alternatives, such as being referred to a pulmonary rehabilitation program, where you would be supervised by a team of healthcare professionals who would guide you in the practice of exercises adapted to your health condition. Discuss this with your physician or healthcare professional.

Keep a positive outlook on life. Be creative, try something different and reward yourself. Your body and spirit will be grateful. Have fun!

HERE IS AN OPPORTUNITY TO PLAN AHEAD!

You have learned new skills to better manage your Pulmonary Fibrosis. You need to integrate these new habits into your daily life, and maintain them on a long term basis, if you would like to see positive results on your health and on your quality of life. It is important to establish a plan by writing down your objectives (the small steps are as important as the big ones!) and the time to achieve them.

My objectives in order to live better with my Pulmonary Fibrosis for the next month:

1. _____
2. _____
3. _____

Are you confident that you can attain your objectives for the next month?

1	2	3	4	5	6	7	8	9	10
not at all confident					very confident				

My objectives in order to live better with my Pulmonary Fibrosis for the next ____ months:

1. _____
2. _____
3. _____

Are you confident that you can attain your objectives for the next ____ months?

1	2	3	4	5	6	7	8	9	10
not at all confident					very confident				

Notes: _____

Patient's signature

Date: _____

Healthcare professional's signature

Date: _____

THE INTEGRATION AND MAINTENANCE OF YOUR PROGRAM

TAKE THE TIME TO REVIEW YOUR OBJECTIVES AND YOUR PLAN.

1. Which objectives have you been able to attain?

2. How did you manage to attain these objectives?

3. Are there any objectives that you have not yet attained? Which ones?

4. What could help you attain these objectives?

Notes:

HELPFUL RESOURCES



Canadian Lung Association

<http://www.lung.ca/>

Alberta & NWT

<http://www.ab.lung.ca>

Telephone: 780-488-6819

British Columbia

<http://www.bc.lung.ca>

Telephone: 604-731-LUNG (5864)

Manitoba

<http://www.mb.lung.ca/index.php>

Winnipeg: 204-774-5501

Westman Region: (204) 725-4230

New Brunswick

<https://nb.lung.ca>

Telephone: 506-455-8961

Newfoundland & Labrador

<http://www.nf.lung.ca>

Telephone: 709-726-4664

Nova Scotia

<http://www.ns.lung.ca/site/>

Telephone: 1-902-443-8141

Ontario

<http://www.on.lung.ca>

Telephone: 416-864-9911

Prince Edward Island

<http://www.pei.lung.ca>

Telephone: 902-892-5957

Quebec

<http://www.pq.lung.ca>

Telephone: 514-287-7400

Saskatchewan

<https://sk.lung.ca>

Toll Free: 1-888-566-LUNG (5864)



RQAM

RÉSEAU QUÉBÉCOIS
DE L'ASTHME ET DE LA MPOC

*La référence des professionnels
en santé respiratoire*

Regroupement Québécois d'asthme et MPOC

<http://www.rqam.ca/>

Telephone: 418-650-9500



Canadian Pulmonary Fibrosis Foundation

<http://www.canadianpulmonaryfibrosis.ca/>

Telephone: 905-294-7645



Canadian Network for Respiratory Care

<http://cnrchome.net/>

Telephone: 905-880-1092

Toll Free: 1-855-355-4672

For a full updated list, you can visit
our website
livingwellwithpulmonaryfibrosis.com

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www.LivingWellWithPulmonaryFibrosis.com



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