

LIVING WELL WITH PULMONARY FIBROSIS BY RESPIPLUS™

A Learning Tool for Patients and Their Families



ADOPTING AND MAINTAINING A HEALTHY AND FULFILLING LIFESTYLE

This guide belongs to:

Healthcare Professional:

Institution:

1ST EDITION JUNE 2016

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



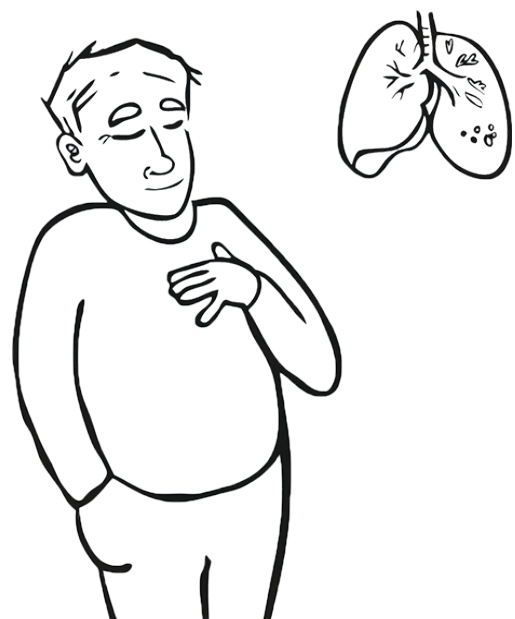
WELCOME TO THE MODULE "ADOPTING AND MAINTAINING A HEALTHY AND FULFILLING LIFESTYLE"

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.

Adopting and maintaining a healthy and fulfilling lifestyle

☐ Being healthy with Pulmonary Fibrosis	5
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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.



ADOPTING AND
MAINTAINING
A HEALTHY AND
FULFILLING
LIFESTYLE

BEING HEALTHY WITH PULMONARY FIBROSIS



Even with a chronic illness like Pulmonary Fibrosis you can still lead an active and fulfilling life. In other words, knowing your disease and taking charge of it on a daily basis will help you live better with your Pulmonary Fibrosis.

LIVING WELL WITH PULMONARY FIBROSIS

Living well with Pulmonary Fibrosis is about adopting and maintaining healthy behaviours in your life. You know that this will mean changing your lifestyle, such as quitting smoking and exercising more. You are ready to make these changes but are not quite sure where to start.

TO CHANGE YOUR LIFESTYLE, YOU MUST FIRST DEFINE HEALTH.

What does health mean to you?

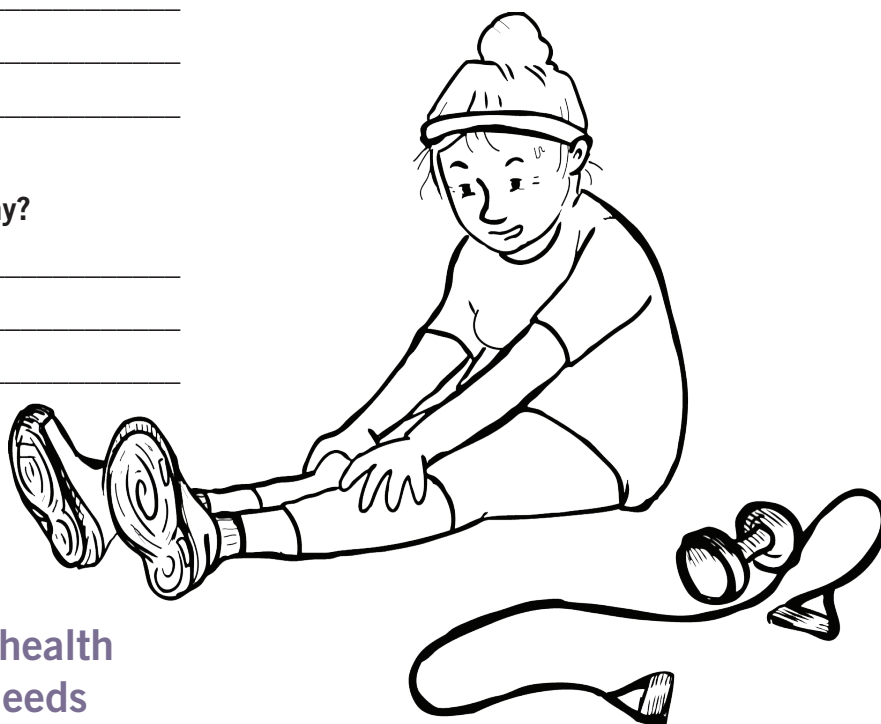
What do you do to stay healthy?

**Taking charge of your health
means knowing your needs
and striving to meet them**

Do you make time for leisure activities?

Why?

How can friends and family help you?



A HEALTHY AND BALANCED DIET

In order to breathe, your body requires a lot of energy or fuel. In fact, a person living with a chronic pulmonary disease such as Pulmonary Fibrosis uses more energy on breathing compared to a person who does not have a lung disease! One way to think of eating is to compare it to filling up a car with gas.

The quality of the fuel counts too.

Why do you think it is important to eat a healthy and balanced diet?

Goal:

To maintain a healthy body weight through a balanced diet.

Benefits:

1. Stores energy
2. Improves quality of life
3. Improves physical capacity
4. Prevents infections

POINTS TO REMEMBER:

- If you are underweight, you can lack energy: you may need to eat more or increase the energy and protein content of your diet.
- If you are overweight, it is harder for your muscles to work and this can worsen your shortness of breath. A balanced and healthy diet can help you achieve gradual weight loss.

THE HEALTHY PLATE

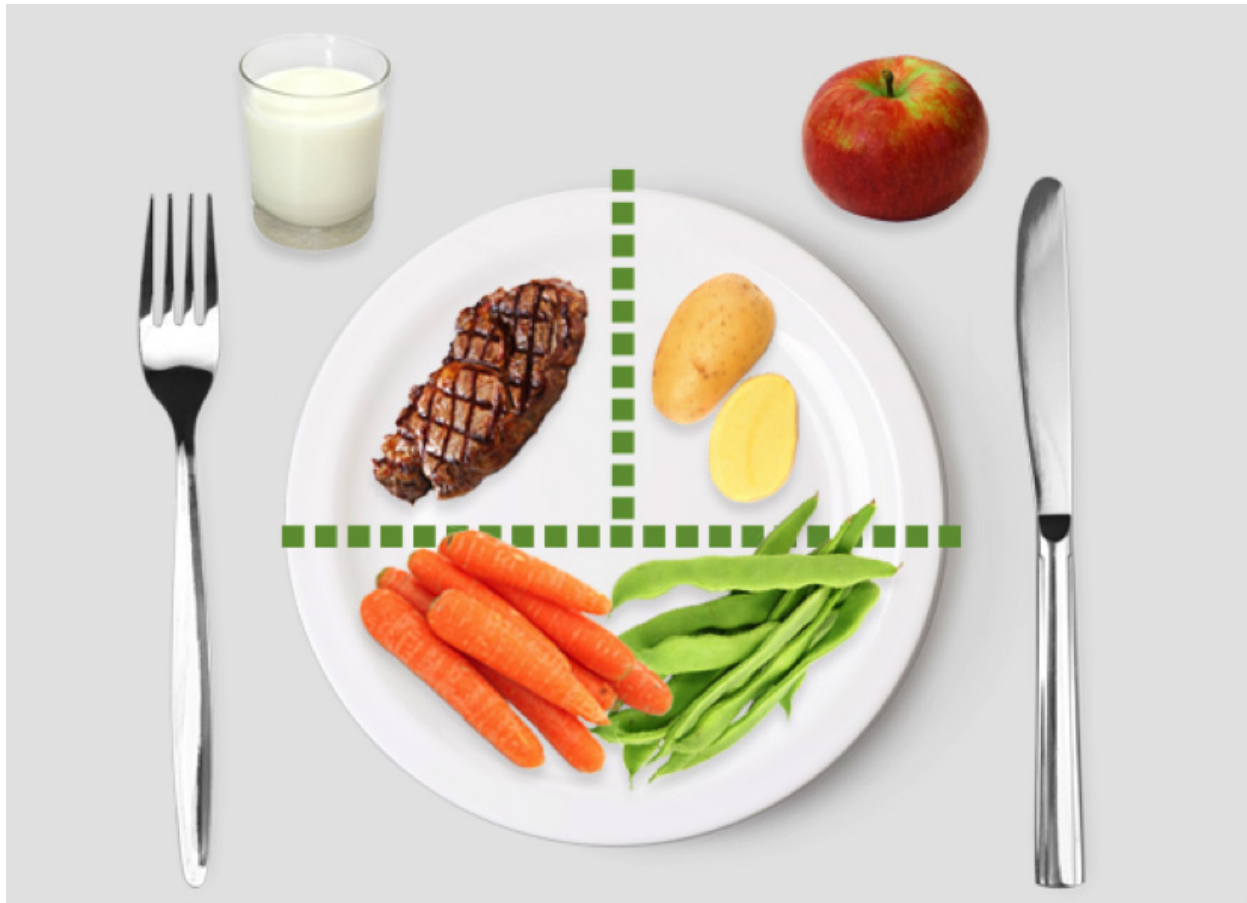
The quality of the food you choose is vital to maintain good health. The same goes for the quantity of food you eat, which often diminishes as the disease progresses.

You need to focus on quantity and quality.

Using the **healthy plate** to build your menu, you will always be on target for a healthy and balanced diet.



THE HEALTHY PLATE



IDEALLY, MAKE SURE THAT:

- **1/2** your plate is filled with **vegetables**
- **1/4** of your plate contains **meat and substitutes**
- **1/4** of your plate contains **grain products and/or starch**
- You complete your meal with a **dairy product or a substitute** and/or a **fruit**, **if you are still hungry.**

reference to healthy plate image

WHAT KEEPS YOU FROM EATING WELL?

1. a) Did you lose weight without wanting to?
 b) Do you think you should lose or gain weight?

2. Do you have any difficulties to shop for food or prepare your meals? Please explain.

3. Are you having difficulties that keep you from eating well (breathlessness, abdominal bloating, digestion, etc.)? Please explain.



STRATEGIES FOR EATING WELL

Within the following examples, identify those corresponding to your current situation. Try to apply the proposed recommendations to minimize the negative impact.

Check if this problem corresponds to your situation	Select recommendations that may be useful
☐ Difficulties in preparing meals	• Plan for meal preparation in large quantities and freeze leftovers • Buying prepared or frozen meals may be an option • Enquire if you could have access to "Meals on wheels" • _____ • _____
☐ Difficulties in grocery shopping	• See if your grocery store offers delivery services • If you are having financial issues, do not hesitate to speak to your health care team. They can help you find solutions (community kitchen, coupons...) • _____ • _____

STRATEGIES FOR EATING WELL

Check if this problem corresponds to your situation	Select recommendations that may be useful
☐ Breathlessness	• Rest before meals • Eat more slowly and divide your portions in several small meals • Eat soft foods to facilitate chewing and reduce fatigue
☐ Early satiety (feeling full after a few bites) and ☐ Anorexia (loss or important decline in appetite)	• Eat foods that are energy-rich (ex. : whole milk 3.25%, cream soups, dish <i>au gratin</i>, nuts, nutritional supplements) • Reduce the amount of liquid ingested with meals. Drink 30-60 minutes before or after your meal to leave room for high energy foods • Take 5-6 small meals instead of 3 large ones • Eat food that you love • If your food has an aftertaste, try to eat it cold. Like this, the aftertaste will be less pronounced
☐ Strategies for Medication side effects	• Please consult documentation pertaining to your medication for guidance

STRATEGIES FOR EATING WELL

Check if this problem corresponds to your situation	Select recommendations that may be useful
☐ Bloating (sensation of distention due to gas)	• Eat slowly avoiding to swallow air • Do not use a straw to drink • Avoid chewing gum and sodas • Avoid foods that cause gas (depending on your tolerance) such as: cabbage, cauliflower, broccoli, onions, melon... • Verify the presence of any intolerance (lactose, gluten) • _____ • _____
☐ Constipation	• Gradually increase your intake of fiber, such as whole grains, legumes, fruits (e.g. prunes), vegetables, etc. • If you eat little, you may opt for fiber supplements. Talk to your pharmacist • Drink enough liquid. Target 6-8 glasses of liquid per day if you do not have any medical restrictions • Take your meals at regular hours to improve your intestinal regularity • Remain active • _____ • _____

Note that if any of these problems becomes persistent or if you are experiencing unwanted weight loss, it is important to be referred to a nutritionist for a complete nutritional evaluation. Your nutritionist will be your best ally to find solutions!

MY NUTRITION GOALS

Goals to improve your eating habits must be tackled one at a time. You should have acquired one habit before going on to the next goal.

Set realistic goals, give yourself time and make sure you have all the help you need (parents, friends, professionals, support groups, books).

My goals	Acquired habits	Plan to integrate this habit		
		1 month	3 months	6 months
I eat 3 meals per day				
I ask for help in meal preparation and grocery shopping				
I make sure to eat protein at each meal (meat/substitute, dairy products)				
I include vegetables in my lunch and dinner				
I include fruits in my breakfast and snacks				
I take at least 2-4 dairy products and substitutes per day				
I choose whole grain cereals and breads				
I favor milk and fruit based deserts				
I drink 6-8 glasses of liquid per day				
Others : _____ _____				

THE IMPORTANCE OF EXERCISE AND PHYSICAL ACTIVITY IN PULMONARY FIBROSIS

Regular exercise and physical activity are essential for your physical and mental well-being. Even doing a small amount of exercise can help, as long as it is done regularly.

GOAL:

- To remain in shape and maintain your functional capacities.

Are you doing some exercise and physical activity on a regular basis? If yes, what? How often?

BENEFITS:

1. Reduces shortness of breath
2. Increases muscle mass and helps maintain bone mass
3. Improves functional abilities and endurance
4. Improves mood and reduces the risk of depression
5. Improves sleep and quality of life

If not, what is preventing you from exercising?

POINTS TO REMEMBER:

- At least 30 minutes a day of physical activity is recommended.
- Aerobic exercise (e.g. walking, swimming, bicycling) and strength training (upper and lower extremities) are two important parts of an exercise program.
- You should have your fitness level evaluated by your doctor or healthcare professional before starting any exercise program.
 - The module “Get moving... Breathe Easy” will guide on how to increase your level of physical activity
 - If you need to start a formal exercise program, talk to your doctor or resource person

PUTTING SLEEP PROBLEMS TO REST

Getting a good night's sleep is very important. You may feel tired over the day when your sleep is interrupted (for example, due to shortness of breath or coughing).

Goal:

To get good, restful sleep.

Benefits:

1. Restores daytime energy
2. Improves the ability to think clearly
3. Reduces anxiety

SUGGESTIONS TO GET A GOOD NIGHT'S SLEEP:

- Exercise, eat well and remain active.
- Maintain a routine.
- Relax before going to bed. Do your relaxation techniques, take a soothing bath and listen to music.
- Avoid heavy meals before bedtime. Heavy meals will take time to digest and will increase your shortness of breath.
- Do not drink coffee, tea or sodas before going to bed. Avoid eating chocolate as well. All of these contain stimulants that will make sleeping difficult.
- Keep your bedroom adequately humidified.
- Avoid talking about stressful things or watching upsetting television programs. They can get your thoughts racing and make it hard for you to fall asleep.

POINTS TO REMEMBER:

- Everyone has trouble sleeping at one time or another.
- There is no "correct" amount of sleep.
- Every person sleeps for a period of time that is healthy for him or her.

If you are still having trouble sleeping and feel tired during the day, talk to your doctor.

A SATISFYING SEXUAL LIFE

Sexuality can be a source of relaxation and pleasure. Respiratory problems and fatigue caused by Pulmonary Fibrosis can have a negative impact on some people's sexual life.

Goal:

To have a healthy and satisfying sexual life to meet your needs and those of your partner.

Benefit:

Can lead to a feeling of well-being for you and your partner.

Some advice:

- Stay in shape with regular exercise. Physical effort during intercourse is equal to climbing a flight of stairs at a normal pace.
- Use the breathing and relaxation techniques taught in *Managing the Impact of Pulmonary Fibrosis* to manage your shortness of breath.

POINTS TO REMEMBER:

- A satisfying sex life is not limited to sexual intercourse. Emotions created by a romantic dinner, soft music and simply touching can also create greater intimacy between you and your partner.
- All your senses are engaged in your sexuality: sight, hearing, scent, taste and touch.

If you have concerns about your sex life, discuss this with your doctor or resource person.

PLANNING FOR LEISURE ACTIVITIES

Even if you have pulmonary fibrosis, it's important for you to plan and do leisure activities you like. Getting involved in leisure activities is a good way to break out of old habits, meet new people and try new things.

What kind of leisure activities do you do?

Are there any leisure activities that you have had to discontinue? Why did you stop?

Do you do leisure activities alone, in groups or with family and friends?

How can your family and friends help you to choose and do leisure activities?

TAKING CHARGE OF YOUR LIFE MEANS DOING MORE OF THE THINGS YOU LIKE

Getting involved in leisure activities can improve your overall health and emotional well-being.

Goal:

To stay physically, intellectually and socially active



Benefits:

1. Provides intellectual stimulation and an opportunity for social interaction.
2. Increases the level of satisfaction with life.

POINTS TO REMEMBER:

- Respect your limitations, but make sure that you are not using them as an excuse to hold yourself back.
- If you feel short of breath, anxious and/or tired in doing a leisure activity, stop it for a few minutes, take the time to breathe, relax and save your energy. Once you feel well, restart doing the leisure activity you were involved in and enjoy it.

HERE ARE SOME EXAMPLES OF LEISURE ACTIVITIES YOU CAN GET INVOLVED IN:

- Painting, sewing, knitting or woodworking
- Reading, writing or learning a foreign language
- Dancing, walking
- Yoga, tai-chi or massage
- Playing cards or lawn bowling
- Listening to music, humming or singing
- Gardening, cooking or computers
- Shopping, going to a coffee shop or out for a romantic dinner
- Going to shows, movies or a flea market
- Travelling
- Volunteer work

SUGGESTIONS:

- Choose a leisure activity that you enjoy. This will give you a better chance of sticking with it.
- Try meeting interesting people who take joy in life and who will show you different ways to do things.
- Choose environments where your symptoms will not be aggravated.
- Respect your strengths and limitations.
- Take time to breathe, relax and save your energy.

THINK OF A SPECIFIC LEISURE ACTIVITY THAT YOU WOULD LIKE TO DO FOR THE NEXT MONTHS

Why did you choose this leisure activity?

Assess your strengths, your limitations and your ability in planning and doing this leisure activity.



TEST YOUR CONFIDENCE LEVEL TO PARTICIPATE IN LEISURE ACTIVITIES

On a scale of 1 to 10, circle the number that best represents the confidence you feel in your ability to do for the next months the leisure activity you chose.

CONFIDENCE LEVEL

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

If you feel that you can do the leisure activity you chose, get involved and have fun!

If you feel that you cannot, what is stopping you?

What can you do to make it happen?

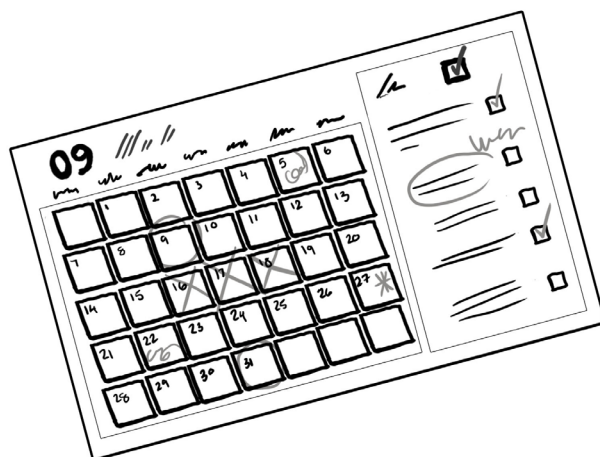
Do not hesitate to talk about it with your resource person or your doctor.

REMEMBER:

Having leisure activities is a good way to keep physically, intellectually and socially active and maintain your health.

PLANNING A TRIP

You want to travel, but you are not sure if you can handle a long trip when you have pulmonary fibrosis. But taking trips – near or far – is possible for many people with pulmonary fibrosis.



So allow yourself to dream a little... But be realistic too.

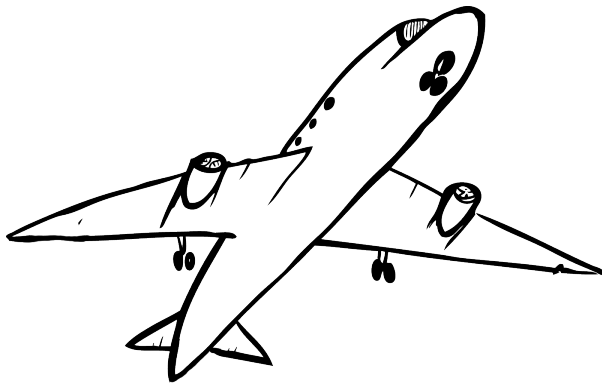
What worries you about taking a trip?

Write down specific concerns and discuss them with your resource person and/or your doctor.

PLANNING A TRIP

Goal:

To visit the people or places you have always wanted to see



Benefits:

1. Increases intellectual, emotional and spiritual stimulation
2. Improves self-esteem
3. Helps to provide a sense of belonging to a wider community

POINTS TO REMEMBER:

- Get advice from your doctor.
- Assess any potential problems you may have when travelling.
- Let your partner or family member know about your concerns and how you plan to address them.

THINK OF A SPECIFIC TRIP THAT YOU WOULD LIKE TO TAKE

What mode of travel would you use to go on this trip?

Why did you choose this mode of travel?

CAR

CRUISE

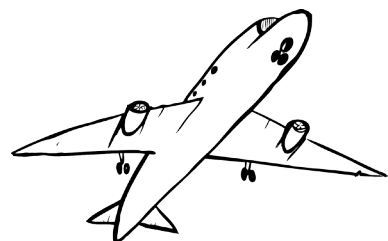
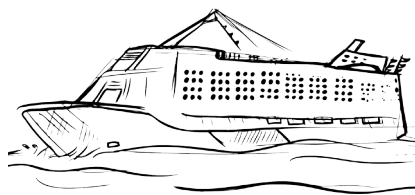
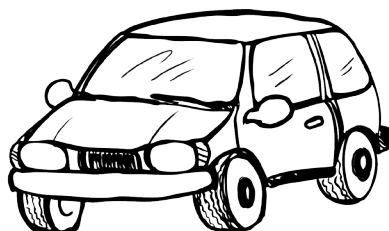
PLANE

Assess your strengths, your limitations and your ability to use these modes of travel.

CAR

CRUISE

PLANE



LET US LOOK AT THE ESSENTIAL ITEMS YOU WILL NEED WHEN TRAVELLING:

- A note from your doctor listing your current medical diagnoses, allergies and medications (including doses and how often you have to take them)
- Enough medication for the duration of your trip and perhaps some extra medication in case there is a delay in returning
- Updated vaccination status for the flu and pneumonia
- Addresses and telephone numbers of medical clinics, hospitals and pharmacies on your travel route
- Contact numbers of your resource person and doctor
- Adequate health insurance
- If you use oxygen, refer to the module *Integrating Long-Term Oxygen Therapy into your life*



TEST YOUR CONFIDENCE LEVEL TO GO OUT ON A TRIP

Now that you have assessed your strengths and limitations, circle the number that best represents your confidence in your ability to go on a trip.

CONFIDENCE LEVEL

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

**If you feel you can travel,
start planning now.**

**Do not hesitate to ask for
help from your resource
person and doctor.**

If you do not think you can take a trip, what is preventing you?

**It is important that you feel mentally and physically
ready to travel. If you are still nervous, talk to your
doctor or resource person at the health centre before
booking your trip.**

LIVING IN A SMOKE-FREE ENVIRONMENT

Adopting and maintaining a healthy and fulfilling lifestyle requires you to acquire good habits, ranging from a healthy diet and regular physical activity to living in a smoke-free environment.

QUITTING SMOKING

Quitting smoking is one of the things that you can do to improve your breathing and avoid aggravations.
Ask people not to smoke around you



How do you think quitting smoking will affect your health?

TEST YOUR KNOWLEDGE ABOUT THE EFFECTS OF CIGARETTE SMOKE

Cigarettes contain over 7,000 chemicals. Most of them are poisonous and can cause respiratory disease and/or cancer.	☐ true	☐ false
Second-hand smoke is not harmful for non-smokers.	☐ true	☐ false
It is never too late to quit.	☐ true	☐ false

If you think that you need help to quit smoking, see your doctor or a healthcare professional who can prescribe medications to help you quit smoking and support you on your path to stop smoking. You might also want to join an anti-smoking program in your region. Consult our section **Helpful Resources** on page 36 for more information.



QUITTING SMOKING

Goal:
To stop smoking.

Benefits:
1. Reduces cough and sputum
2. Reduces the frequency and severity of respiratory infections
3. Reduces the risk of heart attack and cancer

Smoking is an addiction that often takes many years to control. Be patient with yourself. There are many ways to improve your chances of success in quitting smoking.

Here are some suggestions:

MEDICATIONS

- Using medications helping smoking cessation could double your chances of success.
- Products that can help you stop smoking include:
 - Nicotine replacement therapy such as patches, gum, lozenges, inhalators and oral spray.
 - Non-nicotine treatments (tablets) are only available on prescription. These medications work in the brain to help reduce the cravings for cigarettes and withdrawal symptoms.
- Talk to your local smoking cessation specialist, doctor or pharmacist about the most suitable product for you.

QUITTING SMOKING

SUPPORT AND COUNSELLING

- You can increase your chances of success up to 3 times when you combine medication with counselling. There are group programmes or one-on-one sessions. Talk to a health professional, for example, your local smoking cessation specialist, doctor or pharmacist.
- Call the toll-free quitline in your area. Quitlines are free hotlines to help people who want to quit or to learn more about quitting.
- You can also call your provincial Lung Association office: they can provide you information about helplines, support groups, and other resources in your area.

OTHER HELPFUL STRATEGIES

PLAN IN ADVANCE

- Select a good time to stop (ideally, a routine day; avoid special events or days when you are feeling sick).
- Remove from your environment all smoking related items (ashtrays, lighters).
- Use a calendar to record your progress.

MANAGE CRAVINGS AND WITHDRAWAL SYMPTOMS

- Delay: Cravings usually pass in 3-5 minutes.
- Drink water, try sugar-free chewing gum (e.g. with nicotine), or eat something healthy and non-fattening.
- Distract: For example, taking a walk can give you energy and take your mind off cigarettes.
- Deep breathing can help you to relax and make cravings go away.

DEAL WITH RELAPSES

- Don't be too hard on yourself. In average, people try to stop between 5-6 times before succeeding. Ask for help.
- Think about what caused you to relapse and try to avoid this in the future.

CHECK YOUR CONFIDENCE LEVEL IN ADOPTING AND MAINTAINING HEALTHY LIFESTYLE HABITS

On a scale of 1 to 10, circle the number that best represents the confidence that you have in your ability to apply the strategies and techniques taught in this section to adopt and maintain healthy lifestyle habits.

1. To live in a smoke free environment?

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

2. To have a healthy and balanced diet?

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

3. To exercise regularly?

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

4. To maintain good sleep habits?

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

5. To have a healthy and satisfying sexual life?

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

CHECK YOUR CONFIDENCE LEVEL IN ADOPTING AND MAINTAINING HEALTHY LIFESTYLE HABITS

6. Do you think that the strategies and techniques taught in this module can help you to adopt and maintain healthy lifestyle habits?

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

7. Do you think that if you adopt healthy lifestyle habits you will be able to improve your quality of life?

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

If you do not feel confident adopting and maintaining healthy lifestyle habits, what are the reasons?

What could you do to feel more comfortable implementing the strategies taught in this module?

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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