

LIVING WELL WITH PULMONARY FIBROSIS

BY RESPIPLUS™

A Learning Tool for Patients and Their Families



MANAGING THE IMPACT OF 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



RESPIPLUS

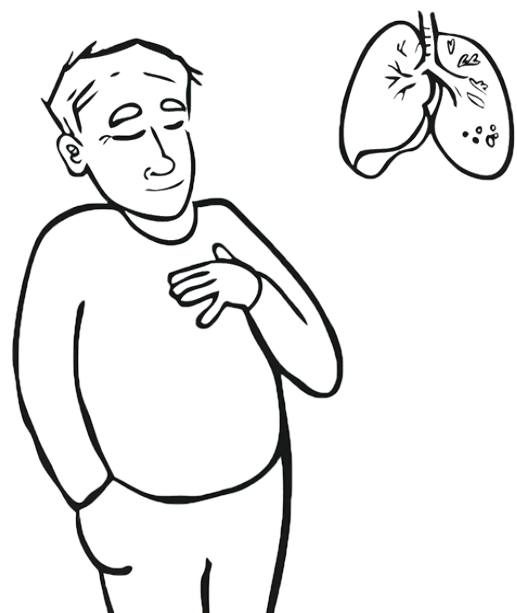
WELCOME TO THE MODULE "MANAGING THE IMPACT OF PULMONARY FIBROSIS"

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.

Managing the Impact of 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.



MANAGING
THE IMPACT OF
PULMONARY
FIBROSIS

MANAGING THE IMPACT OF PULMONARY FIBROSIS IN YOUR DAILY LIFE

Stress is a part of life – and even more so when you are living with a chronic illness such as Pulmonary Fibrosis. ***Living Well with Pulmonary Fibrosis*** means knowing how to control your reactions to stressful situations in your life, maintaining a positive attitude and learning to relax.

Stressors are events or situations in everyday life that require change.

Here are some examples of common stressors faced by people with Pulmonary Fibrosis that force them to make changes in their life.

PERSONAL:

- Personal illness/handicap
- Change in self-esteem
- Change in financial status
- Change in habits (sleep, nutrition, exercise, smoking)

WORK, DAILY ACTIVITIES AND ENVIRONMENT:

- Change in ability to perform activities of daily living
- Loss of job, disability leave, retirement
- Moving to a new dwelling

FAMILY AND SOCIAL NETWORK:

- Separation/divorce
- Illness or death of spouse, family member or close friend
- Conflicts with family members or friends

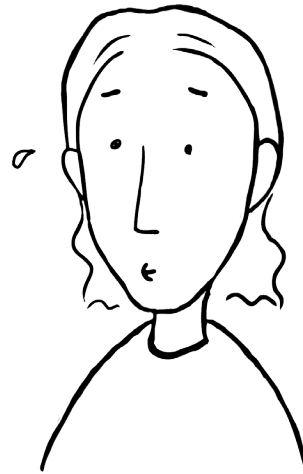
Stress refers to the physical and psychological reactions that a person experiences when faced with stressors.

STRESS REACTIONS

You can react in different ways when facing stressful situations (stressors). Your reaction will have an impact over the way you will cope with them.

Fear is a normal reaction to a present danger.

Symptoms: increased heart rate, shallow, rapid breathing (which is similar to the shortness of breath of Pulmonary Fibrosis), sweating and muscle tension.



Anxiety is a reaction that involves constantly worrying and anticipating stressful situations.

Symptoms: The symptoms are similar to those of fear.

Panic attack is an exaggerated, irrational and often sudden fear or anxiety reaction.

Learning to manage your stress allows you to function at a higher level and to feel more satisfied with life despite the problems that you may be facing.

UNDERSTANDING YOUR ANXIETY RESPONSE

What is the most important stressful situation that you are dealing with these days? Are you anxious about this situation?

Do you have negative thoughts about this situation? If so, what are they?

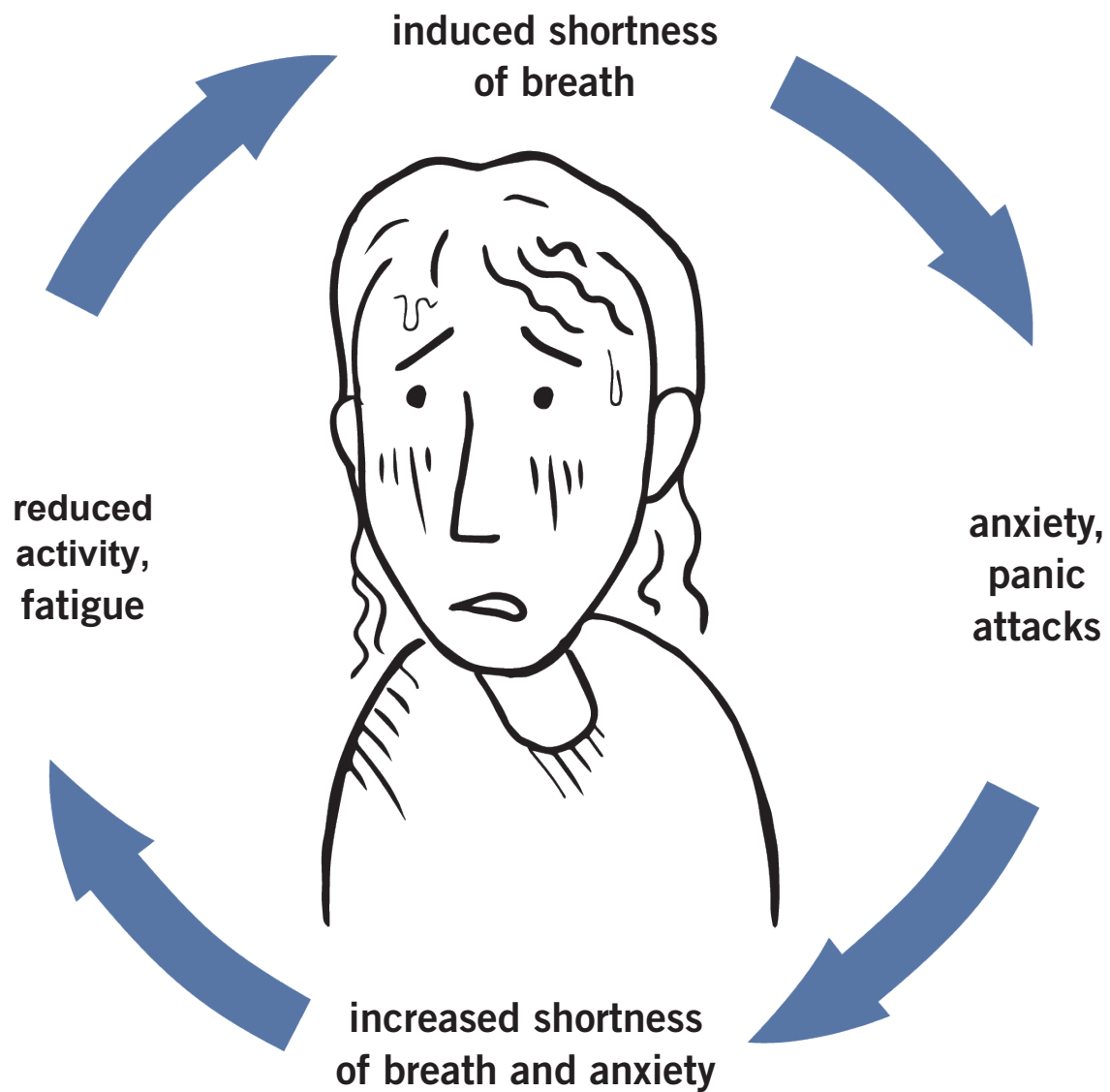
How does your body react when you are anxious? Describe your symptoms?

What do you do when you are anxious?

Can you think of other actions that would help you to better cope with this situation in the future?

Knowing what to do and planning ahead in potentially stressful situations will help you to reduce your anxiety level.

THE ANXIETY-BREATHLESSNESS CYCLE



THE ANXIETY-BREATHLESSNESS CYCLE

- The main symptom of Pulmonary Fibrosis is shortness of breath.
- Shortness of breath can cause anxiety and even panic attacks.
- Anxiety makes you breathe faster, which increases your shortness of breath and as a result, you become more anxious.
- Many people living with a chronic pulmonary disease such as Pulmonary Fibrosis choose to reduce their activities because of their fear of being short of breath, a feeling which can cause great discomfort and can even bring a person to feel as they may be dying from lack of air.
- The less you do, the less you are in shape. You will experience more fatigue, shortness of breath and anxiety.

Managing your anxiety is also very important for managing and reducing shortness of breath.



HOW TO BREAK THE ANXIETY-BREATHLESSNESS CYCLE

Recognize your fears.

Understanding what makes you anxious is the first step to controlling your reaction. Do not be too hard on yourself. Do not think yourself weak for being afraid.

Examine and investigate your fears.

Some of the beliefs that you grew up with may be causing your fears. Ask yourself: Are they based on things that have happened or on things that you fear may happen?

Plan your actions in advance.

You will be less anxious, knowing that you are prepared to deal with stressful situations.

Do things you enjoy.

Reserve room for pleasurable activities in your day.

Try to solve one problem at a time.

Trying to make too many changes at once will only make you anxious.

Let yourself make mistakes.

For most problems, there are a number of possible solutions. If you do not succeed at one thing, try again, taking a different approach if needed.

Maintain a positive attitude.

Your mental health will improve along with your problem-solving ability. Try to concentrate on what is positive in your life.

Use humour.

You can help reduce your stress and create a positive atmosphere.

If you feel uneasy, ask questions and find answers.

Do not hesitate to talk to the people close to you about your feelings and your condition. Do not hesitate to consult a healthcare professional if needed.

Learn to relax, take the time to breathe and save your energy.

You can use the relaxation and breathing techniques as well as the energy saving strategies that you will be learning in the following pages.

Can you think of two others?

RELAXATION TECHNIQUES

Experiencing shortness of breath can be frightening for people suffering from chronic pulmonary diseases such as Pulmonary Fibrosis. Learning to stay calm and take the time to breathe when you feel short of breath can get your breathing – and anxiety – back under control.

What do you do to relax?

If you have difficulty relaxing, what are the reasons?

Goal:
Relax your body and quiet
your mind.



Benefits:
1. Allows you to be in better
control of your emotions
2. Slows your breathing and
reduces muscular tension

MENTAL IMAGES (VISUALIZATION)

People can picture different images. One way to think of them is as “mental movies” running through your mind. These images can be of persons, places, things or accomplishments and they can be positive or negative. For example, it is common for people who suffer from chronic illnesses to be preoccupied with thoughts of how they used to be and everything that they have lost.

It is easy for them to forget that they still have many wonderful things in their lives.

Negative, stressful thoughts use up energy and make you feel tired.

What do you think will happen if you picture yourself as being afraid and hopeless?

What do you think will happen if you picture yourself as being strong and capable?

You will probably feel happier or more confident.

As you can see, it is difficult to dispute the power of an image.

REMEMBER:

- Your attitude is important.
- Optimists tend to seek solutions to problems, whereas pessimists tend to dwell on their worries and fears.

VISUALIZATION TECHNIQUES

Now create your own positive image using a visualization technique: positive thinking.

In this technique, you focus your attention on a positive mental image.

Think of what you already have, what you have the power to improve in your life, and what would make you happier.



Describe your image.

POSITIVE THINKING

1. Concentrate on a positive image.
2. Begin to relax.
3. Use all your senses (i.e. sight, sound, touch, taste and smell) to make your image seem more real. For example, if you are visualizing yourself on a cruise, see the clear blue sky, the sparkling water and the wonderful scenery.
4. End this visualization exercise by retaining your image.
5. Do these exercises (at least) once a day.

PURSED-LIP BREATHING

Pursed-lip breathing is a technique recommended for people having chronic obstructive pulmonary diseases (COPD) such as emphysema, chronic bronchitis, asthma. It helps them to prevent and reduce shortness of breath. This technique can also help people with pulmonary fibrosis to keep calm and better control shortness of breath. Learning how to inhale through your nose and slowly exhale through your lips can help to relax, decrease anxiety and gain control over your own breathing.

Have you heard about the pursed-lip breathing technique? If so, are you using it? How and when?

Goal:

With this technique, you breathe in through your nose and you breathe out slowly, which allows you to return to your normal breathing pattern and feel in control.

Benefits:

1. Reduces breathing frequency and shortness of breath
2. Helps you return to your normal breathing pattern
3. Increases your sense of control over your own breathing

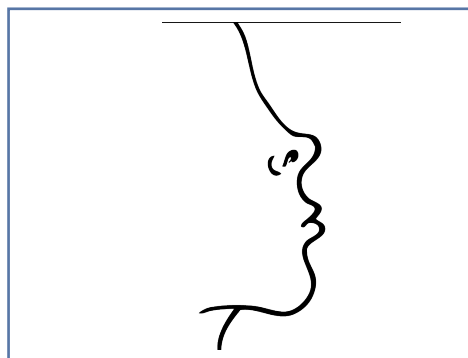
POINTS TO REMEMBER:

- The focus should be on expiration.
- Expiration should be made longer, but not forced.

PURSED-LIP BREATHING

STEPS

1. Inhale slowly through your nose until you feel that your lungs are filled with air.
2. Purse your lips as you would if you were whistling or about to kiss someone.
3. Exhale slowly while keeping your lips pursed. Make sure to take longer to breathe out than you would to breathe in.
Remember to keep your lips pursed.
 - Inhale 1...2...
 - Exhale 1...2...3...4...
4. *Do not force your lungs to empty.*
5. Continue to pursed-lip breathe for at least 5 minutes.



POINTS TO REMEMBER:

- Take your time. Practice is the key to success.
- First, learn to practice this technique at rest until you master it; then when you feel short of breath, stop and take the time to breathe by applying pursed-lip breathing

ENERGY CONSERVATION PRINCIPLES

Staying active and keeping up with your routine is important when you have Pulmonary Fibrosis. Learning how to manage your breathing when performing your day-to-day activities will help you save energy and prevent fatigue.

Goal:

To better perform the daily activities that cause fatigue and shortness of breath.

Benefits:

1. Minimize fatigue and shortness of breath.
2. Better perform daily activities according to your level of energy.

THE 5 PRINCIPLES

1. Prioritize your activities
2. Plan your schedule within your limits
3. Pace yourself and work within your limits
4. Arrange your environment to reduce shortness of breath
5. Keep a Positive attitude and relax

ENERGY CONSERVATION PRINCIPLES

PRIORITIZE YOUR ACTIVITIES

- Evaluate what you have to do and what you would love to do.
- Eliminate activities that are not necessary.

PLAN YOUR SCHEDULE WITHIN YOUR LIMITS

- Stay active within your limits.
- Plan a realistic schedule for the day, week or month.
- Try to schedule the activities that require more energy (e.g. grocery shopping, medical appointments, vacuuming), at the time of day you have the most energy.

PACE YOURSELF AND WORK WITHIN YOUR LIMITS

- Understand your limits and respect them.
- Slow down your rhythm: a slower and regular rhythm uses up less energy.
- Slow down when you speak, laugh, eat or cough, since these actions can interrupt your regular breathing rhythm, causing shortness of breath.
- Alternate heavy and light tasks, e.g. don't go grocery shopping the same day you're vacuuming.
- Sub-divide difficult tasks into smaller steps.
- Include relaxation breaks in your schedule.
- Get a good night's sleep.

ENERGY CONSERVATION PRINCIPLES

ARRANGE YOUR ENVIRONMENT TO REDUCE SHORTNESS OF BREATH

- Be aware of what movements (e.g. bending or reaching) cause you more shortness of breath or fatigue.
- See how you can organize the storage spaces in your house to reduce the need for reaching and bending.
- Try to work with your elbows and/or forearms supported.
- Avoid carrying heavy objects. Pushing, pulling or sliding objects is less demanding.
- When you must carry something heavy, hold it as close to your body as possible.
- Work at a height that allows you to keep a good posture.
- If you feel tired, perform most of your activities while sitting (you will use less energy sitting than standing).

KEEP A POSITIVE ATTITUDE AND RELAX

- Try to be patient and tolerant towards yourself and your family and friends.
- Keep your sense of humour.
- Visualize yourself as a person who makes the most of what they have, rather than as a victim of your disease.

**How would you apply some of these principles when doing some of your daily activities?
Give some examples.**

CHECK YOUR CONFIDENCE LEVEL IN MANAGING YOUR STRESS AND BREATHING

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 module.

1. To control your reactions when facing stressful situations?

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

2. To use the relaxation techniques taught in this module?

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

3. To use the breathing techniques taught in this module?

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

4. To manage your breathing during an attack of shortness of breath?

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

CHECK YOUR CONFIDENCE LEVEL IN MANAGING YOUR STRESS AND BREATHING

5. To use the energy conservation principles taught in this module?

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

6. Do you think the relaxation techniques taught in this module can help you to better manage your stress and anxiety?

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

7. Do you think the breathing techniques taught in this module can help you to better manage your shortness of breath ?

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

8. Do you think the energy conservation principles taught in this module can help you to better manage your fatigue?

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

CHECK YOUR CONFIDENCE LEVEL IN MANAGING YOUR STRESS AND BREATHING

If you feel confident in managing your stress and breathing, continue to apply during your daily activities the relaxation and breathing techniques and energy conservation strategies taught in this module.

If you do not feel confident managing your stress and breathing, what are the reasons?

What could you do to feel more comfortable using the techniques and 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)



Regroupement Québécois d'asthme et MPOC

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

Telephone: 418-650-9500



Canadian Network for Respiratory Care

<http://cnrchome.net/>

Telephone: 905-880-1092

Toll Free: 1-855-355-4672



Canadian Pulmonary Fibrosis Foundation

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

Telephone: 905-294-7645

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

Notes:

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