LIVING WELL WITH
PULMONARY FIBROSIS
BY RESPIPLUS™

A Learning Tool for Patients and Their Families

PULMONARY FIBROSIS AND END OF LIFE

This guide belongs to:

Healthcare Professional:

Institution:

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The skills you need to manage your Pulmonary Fibrosis

Pulmonary Fibrosis (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.

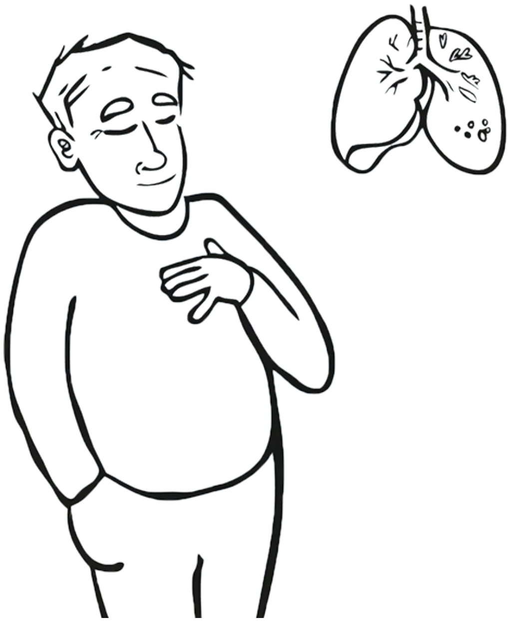
On behalf of Team RESPIPLUS

RESPIPLUS

WELCOME TO THE MODULE "PULMONARY FIBROSIS END OF LIFE"

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.

Pulmonary fibrosis and end of life



PULMONARY FIBROSIS AND END OF LIFE

WHAT TO EXPECT

Discussions about end of life may make you feel uncomfortable at first and that's normal. However, by having these discussions with your doctors and your loved ones, you will become more knowledgeable, and know what to expect if your disease progresses. You will be also in a good position to make clear choices about the care you want and express them to your family and your doctor.

Most types of pulmonary fibrosis will progress over time.

The course of the disease can importantly vary between each patient and each diagnosis. It can even change over time for the same patient. Having a conversation about your ***prognosis*** with your doctor can help answer many of your questions.

Doctors can't predict the future and you may feel they can't accurately answer questions like "how much time do I have". Your doctors are not trying to hide information; the nature of pulmonary fibrosis is sometimes unpredictable. ***Prognosis*** can also change over time and it is a good idea to repeat this kind of discussion with your doctor especially if your clinical condition is changing.

Here are some questions you can ask your doctor to facilitate the discussion about prognosis and disease evolution:

1. **What can I expect in the next couple of months, next year?**
2. **What symptoms can I expect?**
3. **What kind of treatment will I need?**
4. **Will I need oxygen therapy?**
5. **Are there things I can do to plan ahead and be more prepared?**

It is useful to discuss your concerns about end of life with your family and medical team. You can ask questions, prepare yourself and be more aware of the available resources in order to make the process easier.

WHAT CAN I DO TO PLAN AHEAD?

End of life decisions can be tough and very emotional to make, discussion with your family and medical team can help you figure out what you wish and ease the anxiety associated with those decisions.

Expressing what you want for your end of life wishes, in your advance directives, can avoid potential painful conflicts in your family.

Advance care planning or advance medical directives are decisions you can make to provide instruction for your future medical care in situations such as end of life.

It's very important that you discuss with your family or close friends your end of life wishes and make sure they understand well what medical care you want in case you become unable to express your wishes.

You should write down on paper your advances medical directives, sign it in the presence of a witness (family member, a close friend, your doctor or a health care professional) and make sure they are easily available at home and in your medical chart. Taking all these necessary steps can ensure your wishes will be respected when you may not be able to express them yourself.

WHAT CAN I DO TO PLAN AHEAD?

For example, you may want to reflect on things like resuscitation and ventilators.

RESUSCITATION

Resuscitation or cardiopulmonary resuscitation (CPR) is the procedure that medical professionals perform on patients when their heart stops beating (cardiac arrest). It involves repetitive chest compressions. The goal of CPR is to maintain the circulation until the heart can be started again (this is usually done using defibrillation).

In patients who are really sick, it is less likely that CPR will be effective or successful. You may want to discuss with your family and your medical team about whether or not you want CPR to be performed.

VENTILATORS

When someone is unable to breathe on his/her own, doctors can install a tube in this person's throat so that it can be connected to a machine (ventilator) that delivers oxygen through the tube. When your lungs are really sick and you are being put on a ventilator, it is possible that you may never recover enough to breathe on your own and be weaned off the ventilator. You may want to discuss with your family and your medical team about whether or not you want to be put on a ventilators.

REMEMBER:

The choices you make about end of life can be re-evaluated with you and you can rewrite your advance medical directives at any time. They are part of a dynamic process. They do not force you into one path.

NEARING THE END OF LIFE

Sometimes, pulmonary fibrosis can progress to a point where it becomes very severe and you know that you may have limited time to live. Learning your lung disease has become very advanced can be difficult to hear and thinking about death can be scary.

YOU MAY HAVE SOME QUESTIONS SUCH AS:

1. **Will I feel like I am suffocating?**
2. **Will I be in pain?**
3. **Can I die at home?**
4. **What will happen when I die?**

WILL I FEEL I AM SUFFOCATING?

End of life care means alleviating suffering, providing comfort, preserving quality of life and offering support.

Often, Oxygen and appropriate medications are given to relieve symptoms that cannot be controlled anymore. Opioids such as morphine can be prescribed to relieve severe shortness of breath. Anxiolitics can also be prescribed if needed to help decrease anxiety and prevent panic attacks.

Near the end of life, medications can help decrease the secretions and sedatives can be used to optimize your level of comfort if necessary. Your medical team, in collaboration with you and your family will work to make sure your level of comfort is optimal.

NEARING THE END OF LIFE

CAN I DIE AT HOME?

It is possible to die at home if that's what you wish. However, this requires discussion and preparation with your family and medical team. Near the end of life, you will require constant help and care. This can be provided by home care services or palliative care resources. Ask your doctor what palliative care resources are available in your area.

For many different reasons, it is possible you will change your mind and decide you do not wish to die at home. Different resources are available to you. Palliative care homes or palliative care hospital units can offer quality end of life care. Your doctor and medical team can give you more information about the resources available in your area.

Make sure you discuss your end of life wishes with your family. Take the time to put in order your personal papers and make your funeral arrangements.

NEARING THE END OF LIFE

WHAT WILL HAPPEN WHEN I DIE?

At the end of life, you can expect to become progressively less active and need to be spending more time in bed. It is possible you will become more somnolent and will require to sleep more and more until you eventually lose consciousness.

You may experience episodes of agitation, anxiety or confusion. At the very end, your breathing will slow down and become more superficial. The respiration can become very slow with long pauses.

Your loved ones and the palliative care medical team will be there with you until the end to make you feel safe, comfortable and in peace.

REMEMBER:

Even if you have read this module, don't hesitate to discuss with your family and medical team your concerns, fears and questions about end of life. There are tools and resources that can make the process easier.

HELPFUL RESOURCES

THE LUNG ASSOCIATION™
L'ASSOCIATION PULMONAIRE

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 Québecois d'asthme et MPOC
http://www.rqam.ca/
Telephone: 418-650-9500

CANADIAN PULMONARY
FIBROSIS FOUNDATION

Canadian Pulmonary Fibrosis Foundation
http://www.canadianpulmonaryfibrosis.ca/
Telephone: 905-294-7645

Réseau canadien pour les soins respiratoires
Canadian Network for Respiratory Care

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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ACKNOWLEDGEMENTS

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