



For caregivers

Supporting your loved one on treatment with OFEV[®] (nintedanib)

To learn more about treatment of idiopathic pulmonary fibrosis (IPF), scleroderma lung disease or progressive fibrosing interstitial lung disease (PF-ILD) with OFEV, please read the accompanying patient booklet.



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Before you can care for someone else, you have to take care of yourself

Caring for someone who has IPF, scleroderma lung disease or progressive fibrosing ILD is emotionally tough, especially when that person is a loved one. At times it may feel like you have taken on more than you can handle, and it is understandable that you may sometimes feel you are overwhelmed or exhausted.

A big part of being a good caregiver is taking care of yourself too – both mentally and physically. Sometimes, it is easy to set your personal needs to the side, but if your own health becomes compromised you may find it harder to provide the level of care that you want to. Making time to also focus on your own well-being helps you have the energy and focus to take care of someone else.

Caring for someone with IPF, scleroderma lung disease or progressive fibrosing ILD can be challenging. This booklet is designed to provide you with information, insights, resources, and tips to help make coping easier and help you meet the challenge of providing excellent care – for both your loved one and yourself.

In caregiving, communication is key

Share information with all caregivers

Some caregivers live with a patient. Many caregivers do not – you may be a family member, a friend, a neighbour, or someone who provides care for a living. It is important that all people providing some aspect of care to a person living with IPF, scleroderma lung disease or progressive fibrosing ILD share information about the patient’s treatment and health.

Involve healthcare providers in the conversation

Over time, the treatment plan may change. Be sure to ask the doctor or other healthcare provider questions each step of the way. Discuss whatever is important to you and the person you care for. The doctor will understand your priorities and can spend more time discussing them with you.

Keep a list of all the patient’s doctors and medications where you can find it easily, such as on the refrigerator or on your phone.



Some things to know about IPF, scleroderma lung disease and progressive fibrosing ILD



In IPF, scleroderma lung disease and progressive fibrosing ILD, **fibrosis**, or **scarring**, develops in the lungs. Fibrosis causes lung tissue to become **thickened** and **stiff**.

Fibrosis in the lungs caused by IPF, scleroderma lung disease and progressive fibrosing ILD is not reversible.

For more information on IPF, scleroderma lung disease and progressive fibrosing ILD, please refer to the patient booklet in this kit.

Monitoring

When you are caring for someone with IPF, scleroderma lung disease or progressive fibrosing ILD, it can be helpful to understand and monitor their symptoms. Make a note of any questions you and your loved one may have so you can discuss them with the healthcare team.

Common symptoms of IPF, scleroderma lung disease and progressive fibrosing ILD include:



Shortness of breath



A dry cough



Tiredness and weakness



Loss of appetite



Weight loss

Be an advocate

As a caregiver, you support comprehensive care for your loved one in several key areas. Because you often know the person very well, you are in the best position to speak up on their behalf and to ask the difficult questions. One of your jobs as a caregiver is to seek out the appropriate care, at the appropriate time.



Potential members of the healthcare team

People with IPF, scleroderma lung disease or progressive fibrosing ILD are usually cared for by many different doctors and healthcare professionals. This is sometimes referred to as a **multidisciplinary team**. Each of these medical professionals plays a specific role in managing the patient's overall care.

As the caregiver, if you have any questions, do not hesitate to ask them. Staying engaged is an important part of care for both the patient and the caregiver. Write down the names and phone numbers of your loved one's healthcare team, so that you have them all in one place.

Healthcare team

Family doctor - Will continue to be involved in and provide regular care to patients.

Respirologist - Specializes in respiratory diseases; involved in the steps and determination of the diagnosis and treatment plan. Patients may have 1 or 2 respirologists involved in their management and care.

Rheumatologist - Specializes in connective tissue diseases such as scleroderma, including scleroderma lung disease; involved in the steps and determination of the diagnosis and treatment plan. Patients with scleroderma lung disease are typically treated by both a rheumatologist and respirologist.

Nurse/Nurse Practitioner - Specially trained in caring for people with IPF, scleroderma lung disease or progressive fibrosing ILD; will work closely with the respirologist to help coordinate and manage care and inform the team of any changes or updates.



Healthcare team

Pharmacist - Prepares and dispenses drugs and other medications and helps teach about the treatment.

Respiratory therapist - Provides direct patient care by evaluating, treating, and maintaining lung function.

Others may include:

Registered dietician/Nutritionist - Provides guidance on maintaining a healthy diet through different stages of treatment; can also suggest foods or drinks that may help patients who are experiencing side effects.

Allied healthcare professionals (e.g., social worker, counselor) - Provides counselling that can be helpful in coping with the challenges patients may experience in relation to their disease.

Exercise specialist (e.g., physiotherapist, kinesiologist) - Provides information and guidance to help patients safely stay as physically active as possible; geared to specific needs, capabilities, and interests. Please ensure the patient consults their healthcare team prior to starting any exercise program.

Working while supporting

There is no one size fits all solution for caring for someone while you are working. Take time to think about what support is right for you. It may help to explain the issues you are facing to your employer so that they are aware of the situation if you experience problems or need some time off for doctor appointments or to deal with patient care and support.

You may also be able to discuss flexible ways of working, such as working from home some days or changing your office hours.

Speak to your human resources manager or seek advice from your local employment assistance program to find out what you could be entitled to in the workplace.



Setting and sticking to your own personal goals can help you feel more organized

While caring for someone with IPF, scleroderma lung disease or progressive fibrosing ILD might sometimes limit the things you can do, it doesn't have to rule your life. Spending a little time to think your goals through can give structure and direction to your plans and help you focus your efforts on getting things done. Goals can be short-term, immediate things you need or want to do in your day-to-day life, or bigger and more long term, such as organizing or attending a future social event or taking a holiday.



Breaking big tasks down into several smaller, more manageable ones can make it easier to achieve the things you want.



Drawing up progress charts can help you plan your steps toward each goal and track your success.

Don't be afraid to ask for help

Friends and family members may offer to help. Take them up on it. You can ask each person to help with a task that matches their skills. If you have a friend who is a good cook, ask that person for a homemade meal. If another friend is handy with repairs, ask them to fix things around the house.

How to ask for the help you need



Be prepared.

Have a list ready when people ask how they can help.



Be specific.

“Could you take Dad to his respiratory therapy appointments on Mondays?”



Be positive.

“I really appreciate it when you get groceries for Mom.”



Offer choices.

“I need to get Uncle Bob's prescriptions. Could you pick them up or stay with him while I go?”

Here are some tips fellow caregivers have shared that may make coping easier



- You may appreciate having a friend or family member help with chores, such as shopping or cleaning
- Many communities have organizations that offer home healthcare services – speak to your loved one's healthcare provider to find out about services in your community
- Give yourself a break and if possible, hire an aide to provide short-term care
- Don't become isolated – find caregiver support groups in your area
- Your first responsibility is to your own well-being – that's how you can provide the best care you possibly can

Pay close attention to your physical health

Eating well

The energy and nutrients that allow your body to function well come from what you eat and drink, so it is important to eat a healthy, balanced diet. A healthy diet is one that is full of vegetables, proteins, whole grains, and water, and low in sugar and salt.



Guidelines for getting the daily nutrition you need



Try to make about one-third of your food intake consist of a variety of fruits and vegetables.



Base meals on higher fibre starchy foods like potatoes, bread, rice, or pasta.



Have some dairy or dairy alternatives (such as soy drinks).



Eat some beans, fish, eggs, meat, and other protein.



Choose unsaturated oils and spreads and eat them in small amounts.



Drink plenty of fluids (at least 6 to 8 glasses a day).



If you're having foods and drinks that are high in fat, salt, and sugar, have these less often and in small amounts.

To stay healthy, stay active

There's strong evidence that being physically active can help you lead a healthier and happier life.

Brisk walking or other moderate aerobic exercise for 10 to 20 minutes at least 3 or 4 times a week may lower your risk of many chronic diseases and other health problems. Don't neglect muscle-strengthening activities – doing some moderate or high intensity workout or sporting activity that involves all major muscle groups on 2 or more days a week can provide additional health benefits.

Five tips for getting more exercise

- 1 Choose to walk somewhere** instead of taking the car.
- 2 Take the stairs at work** rather than the elevator.
- 3 Do a few circuits** of the local mall at lunchtime.
- 4 Join a gym** or sign up for some **yoga classes**.
- 5 Put on your favourite song and dance!**

Research shows that physical activity can help:



Boost your self-esteem and mood.



Improve your sleep quality and energy.



Reduce your risk of stress and depression.



Lessen the risk of diseases such as heart disease and stroke, high blood pressure, high cholesterol and type 2 diabetes.

When you get busy caring for someone else, it can be easy to neglect your own needs. Make it a priority to get the rest you need, eat well, exercise regularly, and keep your medical appointments. This isn't being selfish – it is making sure you have the energy and vitality you need to provide the best possible level of care.

Your emotions are important too

The feelings you may experience throughout your journey as a caregiver will be unique to you and to the person you are caring for. However, there are some emotions that are experienced by many people who are caring for people with a serious illness, such as:



Frustration



Impatience



Sadness



Anger



Helplessness

If you recognize that you are feeling sad, angry, or unable to sleep most of the time, you may be experiencing something called “caregiver burnout.” This is when the challenges of providing care become overwhelming and your positive mental attitude can become negative.

In some cases, the normal emotions of caring can lead to depression. Depression can affect different people in different ways, but if you are feeling very down most of the time, it is very important to speak to a healthcare professional about your feelings.

Focusing on the positives can help you see that the care you deliver makes a real difference in the life of the person you are caring for.



Connecting with others can help you avoid caregiver burnout

Finding ways to take a break from caregiving is really important. Caregivers can often feel lonely or isolated when it becomes difficult to take time away from caregiving. Even a couple of hours off once a week can help you maintain social relationships and have a little time to relax. And if you aren't fortunate enough to be surrounded by supportive family and friends, remember that there are many other caregivers who have the same social needs that you do.

Linking up with other caregivers and taking part in caregiver support groups can provide a wealth of benefits, including relief from loneliness, emotional support from others going through similar experiences, practical support for all aspects of caring for somebody with a serious illness, learning about coping strategies that work, and sharing knowledge and advice with others facing similar situations.

If you know other caregivers, perhaps consider setting up your own support network.



The **HeadStart™ Patient Assistance Program** is a great resource for both patients and caregivers, and can link you with caregiver support.



Questions? The HeadStart Program is ready to help

Toll-free information line:

1-844-473-6338

HeadStartOFEV@patientassistance.ca

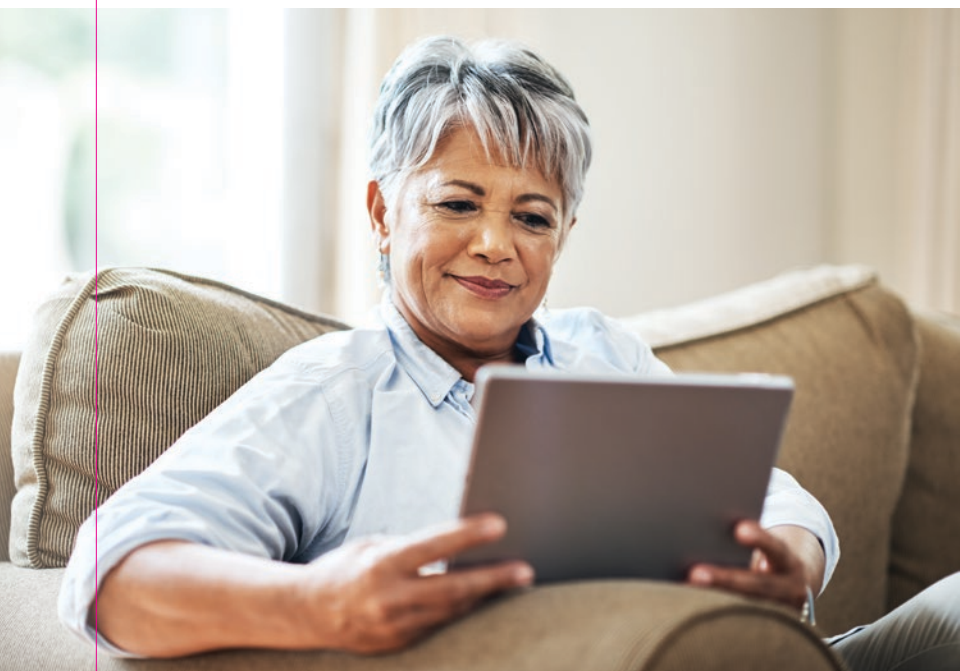
Finding caregiver support and resources – ask your healthcare team or search online

- Type “caregiver support groups” and the name of your town or city into your internet browser and see what comes up.
 - Regional, national, or international caregiver organizations often provide support on their websites or organize local meetings.
- Many institutions support and represent people with IPF, scleroderma lung disease or progressive fibrosing ILD. Try searching for the disease name. Also try searching for support groups for a specific condition, like “idiopathic pulmonary fibrosis” or “scleroderma lung disease”.
- You might also find local caregiver groups by asking at the local library or clinic, or in your town’s newspaper.
- Caregiver conferences can be a great way to find support and feel connected. Search online or ask the doctor/nurse for information on any conferences near you.
- Social media platforms like Facebook or Twitter are a great place to find caregiver groups or those talking about IPF, scleroderma lung disease or progressive fibrosing ILD. These can be a daily source of motivation.
- Remember that as a caregiver, you might be able to get extra financial, practical, or emotional support from your local government or social services.

Mindful, resourceful, joyful – you are doing a good thing

It may not always be obvious, but remember that by helping someone with IPF, scleroderma lung disease or progressive fibrosing ILD, you can have an incredible impact on their overall care, which is something you can feel good about. Finding ways to look after yourself while you're caring for someone else will ultimately benefit both of you.

Notes



Resources and support

The following websites and online resources provide valuable information for patients and their loved ones.

Canadian Pulmonary Fibrosis Foundation

www.canadianpulmonaryfibrosis.ca

Scleroderma Canada

www.scleroderma.ca

Canadian Lung Association

www.lung.ca

Pulmonary Fibrosis Foundation

www.pulmonaryfibrosis.org

National Heart, Lung, and Blood Institute

www.nhlbi.nih.gov

Additional care resources

Community Care Access Centre (CCAC)

healthcareathome.ca

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