

## Activities that you can help with

People with IPF may need help with physical activities that they find difficult because of severe breathlessness on exertion. The following are examples of activities that you could help your loved one with:

- Getting washed and showered. Patients may need help with their oxygen while they bathe.
- Getting dressed. This requires a lot of energy with twisting, reaching and bending down.
- Household cleaning chores and gardening.
- Grocery shopping. The cold air in some supermarkets can trigger coughing and breathlessness in patients.
- Making telephone calls. Your loved one might find it difficult to talk on the phone.
- Checking medication. Two heads are better than one when it comes to checking the names, dose and times of when to take medicines.

## Hospital and GP visits

You will be a great support to the patient if you go with them to their GP and hospital visits. You can tell the doctor about the patient's true state of health and any changes you have noticed.

Let the doctor know about any concerns you may have and ask questions.

It can be hard to remember what the doctor tells you so bring a pen and paper and take notes. If you don't understand what the doctor has said, ask them to explain it again or in a different way.

Be honest and open with your doctor about what is on your mind.

## Home safety tips

- Make sure your house has a working fire alarm and carbon monoxide detector on each level. Check your fire alarms every week. Have an escape plan.
- Don't allow anyone to smoke in your home.
- Never use candles or naked flames near oxygen.
- Don't use products that have a strong smell such as bleach, perfume or aftershave as they could trigger breathlessness in an IPF patient.
- Learn about the patient's oxygen machines. Order more oxygen if their supplies are running low.
- Be careful not to trip over or block oxygen tubing.
- Keep a first aid kit in the house and in the car.

## Finding out more about IPF

As a carer, you may want to find out information about IPF on behalf of the person you are caring for. Be careful what websites you use. Information on some websites is not reliable and might upset or frighten you. ILFA suggests that you:

- read the ILFA resources and information leaflets;
- register to receive the ILFA newsletter;
- attend ILFA Information Days;
- visit our website ([www.ilfa.ie](http://www.ilfa.ie)) and Facebook page for information, advice and tips;
- read *"The Irish Thoracic Society 2012 Guidelines for the Treatment of Patients with IPF"* available from the websites [www.ilfa.ie](http://www.ilfa.ie) or [www.irishthoracicsociety.ie](http://www.irishthoracicsociety.ie).

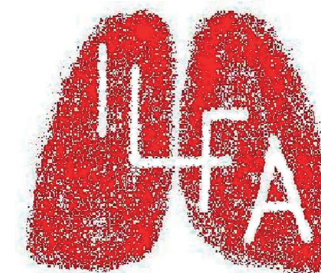
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**Irish Lung Fibrosis Association**

# Advice for carers of people with Idiopathic Pulmonary Fibrosis



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## About this leaflet

The content of this leaflet is based on discussions held at patient support group meetings. This leaflet explains what Idiopathic Pulmonary Fibrosis (IPF) is and describes the important and valued role carers have in caring for people diagnosed with IPF. It provides you with useful tips on how you can help and support someone with IPF and keep yourself well too.

The Irish Lung Fibrosis Association (ILFA) hopes you find this leaflet useful.

## What is IPF?

IPF is a progressive disease that causes scarring (fibrosis) of the lungs. The cause is unknown. Its symptoms include severe breathlessness, coughing, fatigue and low energy due to low oxygen levels in the blood. The symptoms get worse over time. People with IPF can find everyday activities difficult and may need your help. Read the ILFA leaflet entitled "*What is Pulmonary Fibrosis?*" for more information.

## Being a carer

Being a carer can be rewarding and will bring you closer to the person you are caring for. It is also tiring, demanding and frightening as you may be faced with a changing role and have to provide physical, practical and emotional support to the person with IPF.

You are in a unique position to help the person you are caring for and notice how they are coping. You may notice changes in their breathing, daily routine and ability to exercise.

One of the most important things you can do as a carer for someone with IPF is encourage them to have a positive outlook and stay active. Why not exercise with them to keep them motivated and focused on keeping well?

## Caring for yourself

Taking care of your own health and wellbeing will help you give the best support to the person you are caring for. But, be realistic about what you can do, especially if your own health is poor. The following tips outline how you can care for yourself.

- Keep in touch with your friends, and carry on with your hobbies and social interests. Read, listen to music or just relax and unwind when you can.
- Have a rest when the person you are caring for is resting. A power nap for 20 minutes can give you energy.
- Tell your doctor if your own mood is low or has changed. Depression is common in carers. Ask your GP about counselling if you are finding it hard to cope. It is important to recognise if you are feeling stressed, guilty, angry, lonely or frustrated.
- Make sure you get the flu vaccine every year so you do not catch the flu or pass it to your family.
- When pushing a wheelchair, use the muscles in your legs to give you extra power.

## Ask for help

Discuss IPF with the person you are caring for and with your family and friends and the healthcare team supporting you.

- Ask family members and friends for help. Maybe they could help you by doing some shopping, cleaning or gardening or spending time with the person with IPF. Call on them for support if you are having a bad day.
- Be honest and open with family and friends about the support you need.
- Ask your doctor or social worker for help and support.
- Contact an IPF support group.
- Ring The National Careline, a telephone service run by the Carers Association of Ireland for support. Their number is **1800 24 07 24**.

Remember, you can't do everything and you are valued.

## Get organised

- Have a plan in place in case you need medical advice on how to manage your loved one's symptoms. It is important to know who to contact if they have an infection or if their breathing gets worse.
- Keep a diary and a documentation folder with important information such as letters, test results, records of medical appointments and the patient's medications and the doses.
- Plan trips and activities beforehand. Give yourself and the person you are caring for plenty of time to get ready. Always ask for a taxi that is wheelchair accessible or is big enough for any oxygen equipment if necessary. Always bring an emergency back-up supply of oxygen with you in case there are unexpected delays while travelling.
- Ask your employer for flexible working options.
- Speak to a social worker about grants and allowances that you might be able to apply for.
- Learn about the STALL Breathing Technique for people with IPF who are breathless. Contact ILFA to request a STALL Breathing Technique Card and a Medical Alert Card for IPF patients on oxygen. **Call 086 871 5264**

## Emergency numbers

Know how to call the emergency services. Call 112 or 999.

Keep a list with other emergency contact numbers and put it somewhere where you will find it easily. For example, stick it to the back of a kitchen door.

Your list of contact numbers should include:

- family members
- hospital
- GP
- pharmacy
- oxygen company