

Tests and investigations

You will need to have some tests carried out to help confirm your diagnosis and monitor your health. Ask your doctor the following questions;

- What is the name of the test?
- Why do I need this test?
- What will the test involve?
- Do I need to prepare for the test?
- Are there side effects?
- How long will it take to recover?
- Will I need to stay in hospital?
- Do I need to have somebody with me?
- When and how will I get the results?
- What do abnormal results mean?

Take your time when making a decision about your health and taking tests. If you need it, don't be afraid to ask for more time to consider any options that your doctor suggests. Talk about your options with a family member or a friend.

Make an appointment to talk to your doctor about your concerns. Don't be afraid to ask about your test results.

Managing your health

It is important to take a proactive approach to your health, stay active and have a positive outlook.

Keep a diary to keep track of how you are feeling and record any sickness or infections that you have. Write down the dates of your visits to your GP.

Do not take new medicine including over the counter medicine, herbal medicine, or vitamins without your doctor's approval. And never buy prescribed medicines from the internet.

Use your oxygen as prescribed by your doctor. Your oxygen prescription is just as important as your prescribed medications.

Exercise is important to keep active and maintain your level of fitness. Contact ILFA to request a "2000 Steps a Day Challenge" exercise pack.

Remember that you are not alone. Contact ILFA for a list of IPF support groups.

Future planning

It is important for you to have a plan in place in case you need medical advice on how to manage your symptoms. You should know who to call and what to do at night, weekends and bank holidays.

Ask your doctor:

- what should you do if you think you are getting an infection or if your breathing or cough get worse?
- should you get the flu vaccine and pneumonia vaccine?
- can you have a medication and oxygen review if you are not responding to treatment?

Your doctor may discuss palliative care with you. This focuses on relieving your symptoms, maximising your wellbeing and improving your quality of life. This will help you and your family members as IPF progresses.

Finding out more about IPF

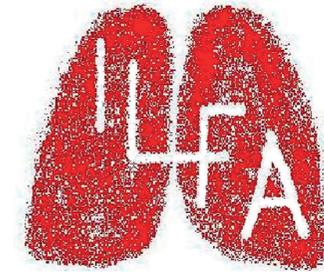
You may want to find out information about IPF. Be careful what websites you use. Information on some websites is not reliable and might upset or frighten you. ILFA suggests that you:

- read the ILFA resources and information leaflets;
- register to receive the ILFA newsletter;
- attend ILFA Information Days;
- visit our website (www.ilfa.ie) 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 or www.irishthoracicsociety.ie.

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Irish Lung Fibrosis Association

Getting the most out of your hospital appointments

Advice for Idiopathic Pulmonary Fibrosis patients



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About this leaflet

The content of this leaflet was recommended by people with Idiopathic Pulmonary Fibrosis (IPF). It explains what IPF is and provides you with tips on how to get the most from your meetings with doctors and other healthcare professionals.

We know that you are probably nervous when you go to meet your doctor and other healthcare professionals to talk about your condition. We encourage you to be brave, to ask the questions you want answered and to expect and get answers that you can understand. Having clear answers to your questions will help you cope with the medical, practical and emotional challenges of living with IPF.

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

What is IPF?

Idiopathic Pulmonary Fibrosis (IPF) is a progressive disease that causes scarring (fibrosis) of the lungs. The cause is unknown. Patients develop severe breathlessness, cough, fatigue (tiredness) and low energy due to low oxygen levels in the blood. The symptoms get worse over time. There is no cure for IPF but some patients may be suitable for a lung transplant. Read the ILFA leaflet entitled "*What is Pulmonary Fibrosis?*" for more information.

IPF can be difficult to diagnose and you may need to have many tests to confirm if you have IPF or another lung disease.

IPF treatment is usually managed by hospital doctors who are experts in respiratory medicine. Your GP (family doctor) can treat and advise you if you are feeling unwell between your hospital visits.

What should I do before I meet my doctor?

Before you meet your doctor, think of the questions you want to ask them and write them down. Talk about the questions with a family member or a friend before you talk to your doctor. You can ask the doctor your questions over several hospital visits rather than in one go.

Questions you may want to find out the answers to are listed below.

- Have I early or advanced IPF?
- Am I a suitable patient for IPF medication?
- Do I need to be seen by an IPF specialist?
- Will I be able to continue working?
- Will I need oxygen?
- Am I suitable for a lung transplant?
- Is there a local IPF support group?
- Are there are pulmonary rehabilitation classes available?

Bring somebody you trust with you to your hospital appointment.

Bringing a spouse, family member or friend with you for support can make you feel more confident. They can also help you to ask questions and get clear information.

Ask and expect clear answers.

- Try to relax.
- It can be hard to take in information about your condition, especially if you have just been diagnosed with IPF. If you don't understand what the doctor has said, ask them to explain it again or in a different way.
- It is hard to remember everything the doctor tells you so bring a pen and paper and take notes.
- If you want a second opinion, tell your doctor. They will understand.

Share information with your doctor

Be honest and open about what is on your mind.

Let your doctor know if you have been ill and needed medicine since your last hospital visit. Tell them if your symptoms have got worse.

Tell your doctor if your mood is low or has changed. Depression is common in IPF patients. Ask about counselling if you think you need it. It can be useful in helping you come to terms with your diagnosis. It is important to recognise if you are feeling stressed, angry, lonely or afraid.

Keep a list of all your medicines, the dose and how often you take it. Bring your list to every appointment. Tell your doctor about any side effects that you notice.

Tell them about your progress and exercise tolerance and if you are doing the *ILFA 2000 Steps a Day Challenge* or pulmonary rehabilitation classes.

Other members of your healthcare team

There are a number of people on healthcare teams. Here is a list of some of the healthcare staff you may interact with and what they do.

A **nurse specialist** will give health advice and support on all aspects of IPF.

A **physiotherapist** will advise you about the best exercises to stay fit and healthy.

A **social worker** will tell you about grants and allowances that you may be entitled to.

An **occupational therapist** will give you advice on how to adapt your home and workplace to your needs.

A **pharmacist** will advise you about suitable medication for you.