Irish Lung Fibrosis Association
www.ilfa.ie

National Patient Charter for Idiopathic Pulmonary Fibrosis

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The National Patient Charter for IPF

The Irish Lung Fibrosis Association (ILFA) aims to support patients diagnosed with Idiopathic Pulmonary Fibrosis (IPF) to ensure they receive the best medical care and support services.

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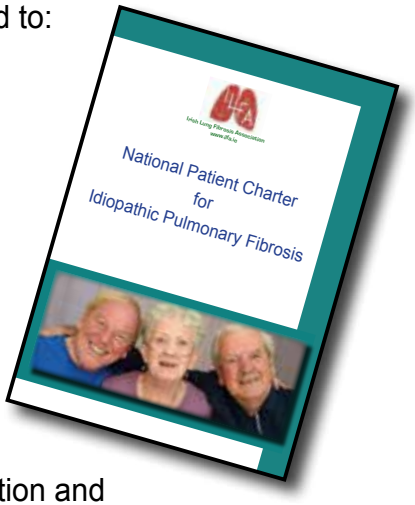

1. Early and accurate diagnosis with multi-disciplinary team input.

2. Clear and concise information about IPF in plain language.

3. Access to appropriate medicines and oxygen therapy.

4. Early referral to pulmonary rehabilitation and exercise programmes.

5. Early referral to the National Lung Transplant Unit for lung transplant assessment, with a minimal emphasis on your age.

6. Access to social, practical and emotional supports.

Introduction

The Irish Lung Fibrosis Association (ILFA) was set up to support patients and families affected by lung fibrosis. ILFA has developed this national patient charter to help you and your family access the best care after you have been diagnosed with Idiopathic Pulmonary Fibrosis.

What is IPF?

Idiopathic Pulmonary Fibrosis (IPF) is a chronic, life-limiting and progressive disease that causes scarring of the lungs. Patients develop severe breathlessness, cough, fatigue (tiredness) and low energy. The cause is unknown and there is no cure.

Why is a national charter needed?

ILFA wants to increase awareness of IPF among members of the public, GPs (family doctors) and healthcare professionals. Most people have never heard of IPF and being diagnosed with this condition can be very frightening and confusing. This charter will help you and your family understand how to access the best IPF treatment, and guide you as you make use of the healthcare system.

Aims of the National Patient Charter for IPF

The aims of the charter are to:

- give you a clear expectation of the standard of care you should receive;
- inform you and your family about the medical treatment and services that you should have access to; and
- make sure that your doctor and other healthcare professionals will be clear on what you expect of them.

What this means for you

If you are diagnosed with IPF, you will need to access ongoing medical and support services to help you manage your symptoms and maintain your quality of life. ILFA hopes that the charter will encourage you to look for the best treatment and support services to help you manage your IPF.

The best things you can do to help yourself adapt to living with IPF are;

- learn more about IPF,
- work closely with your healthcare team and ask them questions, and
- take responsibility for your own health and treatment.

You can contact ILFA to request our patient information resources and register to receive our newsletter to keep up to date with developments in IPF.

How the charter was developed

In 2013, ILFA was asked to hold focus group meetings with patients and carers as part of an international project organised by the European Respiratory Society and the European Lung Foundation.

In these group meetings, patients and carers were asked to share their experiences of IPF on topics such as diagnosis, treatment and quality of life. The world's leading IPF doctors sought patients' views to help them develop new guidelines on the "Management and treatment of Idiopathic Pulmonary Fibrosis".

A **draft charter was prepared** taking into account:

- the feedback from the focus groups;
- important medical references; and
- the goals of the European IPF Patient Charter, which ILFA contributed to.

Six main areas were identified as being important to include in a national charter: diagnosis; clear communication; medicine and oxygen; lung transplant; pulmonary rehabilitation and exercise; and additional support services.

We carried out further consultations with patient support groups, doctors, healthcare professionals and professional organisations to check that the six main points were the right ones to focus on. We have included representative feedback from this at the end of this booklet. The charter was assessed by the National Adult Literacy Agency to ensure that it met plain English guidelines.

ILFA is confident that the charter reflects the needs of IPF patients, carers and healthcare professionals in Ireland. We hope you will find it useful.

The National Patient Charter for IPF

The Irish Lung Fibrosis Association (ILFA) aims to support patients diagnosed with Idiopathic Pulmonary Fibrosis (IPF) to ensure they receive the best medical care and support services.

As an IPF patient, you should be entitled to:

1. Early and accurate diagnosis with multi-disciplinary team input.

2. Clear and concise information about IPF in plain language.

3. Access to appropriate medicines and oxygen therapy.

4. Early referral to pulmonary rehabilitation and exercise programmes.

5. Early referral to the National Lung Transplant Unit for lung transplant assessment, with a minimal emphasis on your age.

6. Access to social, practical and emotional supports.

The National Patient Charter for IPF

1. Early and accurate diagnosis

You should be entitled to an early and accurate diagnosis with multi-disciplinary team input. IPF can be difficult for doctors to diagnose and is often misdiagnosed as another lung condition.

- **Early and accurate diagnosis:** You should receive an early and accurate diagnosis by a specialist doctor. This will help ensure that you can access appropriate treatment in a timely manner.
- **Access to experts:** Respiratory doctors should have access to experts in:
  - radiology (specialists who read x-rays and CT scans); and
  - histology (specialists who look at tissues and cells under a microscope), to help diagnose IPF quickly and accurately.
- **Referral to a specialist IPF centre:** Respiratory doctors should refer people with suspected IPF to a specialist IPF centre for an accurate diagnosis and treatment plan. Here, you should have access to a team made up of:
  - respiratory doctors with experience of IPF,
  - an IPF specialist respiratory nurse,
  - physiotherapists,
  - medical social workers,
  - dieticians, and
  - palliative care and end-of-life care services.
- **Shared care:** If possible, your care should be managed between your local hospital or GP (family doctor) and the specialist IPF centre.

2. Communication and information

You should receive clear and concise information about IPF. This will help you to understand and manage your condition as independently as possible.

- **Diagnosis:** Doctors should deliver a diagnosis of IPF in a clear and a sensitive manner, allowing time for discussion and questions during appointments.

- **Plain English:** All communication about IPF, both verbal and written – between you, your healthcare team and your caregivers should be in plain English. Doctors and healthcare professionals should check that you understand what they are saying and encourage questions.

- **Clear written information:** Written information should be given to you when possible. Leaflets and support materials are available free of charge from ILFA.

- **Online information:** Healthcare professionals should give you and your family advice on how to access accurate online information about IPF.

- **Information on treatment plans:** You should be given full information about your medicine and other treatment options, including pulmonary rehabilitation, exercise and oxygen.

3. Medicine and oxygen

You should be entitled to appropriate medicines and oxygen therapy. There is no cure for IPF. Some medicines can slow down the rate at which the disease progresses in patients with mild to moderate IPF, but they do not cure IPF. Other medicines and oxygen may be prescribed to treat your symptoms and improve your quality of life.

- **Treatment for IPF:** Your doctor should give you full information when you are diagnosed about available treatments, including medication and oxygen.

- **Appropriate medicines:** Your doctor should prescribe appropriate medicines. They should explain the benefits and limitations of the medicines and potential side-effects.

- **Medical oxygen:** Your doctor should prescribe medical oxygen (also called supplementary oxygen) for you if you need it to help your breathlessness and to improve your quality of life. Your doctor or physiotherapist should regularly review your oxygen prescription to make sure it is still appropriate.

- **Oxygen supplies:** You should be entitled to enough oxygen to allow you take part in everyday activities including going out, socialising with friends and exercising.

- **Support services:** You should be offered advice, support and counselling from healthcare professionals to help you adjust to using oxygen.

4. Pulmonary rehabilitation and exericse

Your healthcare professional should refer you to pulmonary rehabilitation classes and encourage you to exercise. Research has shown that pulmonary rehabilitation and regular exercise have positive benefits for IPF patients. Benefits include increased strength, improved breathing and mobility.

- **Early referral:** You should have early referral to a pulmonary rehabilitation service with exercises tailored to your needs.

- **Home exercise:** You should be given information about home-based exercise programmes that you can use if there are no pulmonary rehabilitation classes available.

  Contact ILFA and ask for our 2000 Steps a Day Exercise Challenge walking pack and Exercise DVD for Lung Fibrosis Patients - they're ideal for home exercise.

- **Access to pulmonary rehabilitation programmes:** You should have access to pulmonary rehabilitation programmes on an ongoing basis in order to benefit from regular supervised exercise.

5. Lung transplant assessment

Your healthcare team should refer you early to the National Lung Transplant Unit at the Mater Misericordiae University Hospital for lung transplant assessment. A lung transplant is an effective treatment for IPF. It should be considered for all patients and discussed at an early opportunity.

- **Early referral:** If you have good general health apart from your IPF, you should be referred early for lung transplant assessment, with a minimal emphasis placed on your age.

- **Lung transplant decisions:** Your healthcare team should make sure that you and your caregivers understand the reasons for being accepted, or not accepted, on the lung transplant waiting list and what this will mean for you and your family.

- **Exercise to maintain health:** Your healthcare team should encourage you to take part in pulmonary rehabilitation classes and exercise. This will help you maintain your health and fitness before and after a lung transplant.

6. Additional support services

Your healthcare team should help you identify and access social, practical and emotional supports to help you cope with your IPF. IPF affects each patient differently and the level of support that you may need can change as your disease progresses. Your healthcare team should provide a **'total patient'** care approach. This approach takes your physical, emotional, social, economic, and spiritual needs into account.

- **Counselling:** You and your carers should be offered professional counselling at the time of your diagnosis, as your IPF progresses or when you ask for help.

- **Patient supports:** Healthcare professionals should inform you and your family members about patient organisations and local support groups – they can be very helpful.

- **Practical supports:** Your healthcare professionals can advise you about the practical supports available including help from social workers, counsellors, community physiotherapists, public health nurses and home help services.

- **Palliative care:** You should be referred early to a palliative care team if your health is getting worse. Palliative care is often wrongly associated with caring only for cancer patients at the 'end of life'. In fact, palliative care can be useful at any time for IPF patients and can help when you develop increasing cough, breathlessness and fatigue (tiredness).

- **Planning for the future:** You should be asked about your future care preferences if your health starts to get worse. For example, you might like to decide on where you would like to be looked after (at home, in hospital, a nursing home or in a hospice). You may also like to decide on medical treatment decisions, and if you have any cultural or religious beliefs that should be considered as part of your care.

General feedback

ILFA was encouraged by the positive responses to the draft charter following the consultation process - all those involved welcomed the development of a national charter for IPF. All submissions were reviewed and considered when finalising the national charter.

An overview of some of the supportive comments received by ILFA is presented below.

Comments received


"I think the charter looks good, it's quite clear and concise. It's a very good idea that patients can clearly see a route to a better life where possible."
"Well done to all and keep up the good work it is very much appreciated!"
"I have read the charter and fully support this initiative. Really good work."
"I found the charter very clear and relevant for optimal treatment and care. It certainly captures the patient priorities."

Acknowledgements

ILFA would like to thank all those who took part in the focus group meetings in 2013 and shared their experiences of living with IPF. The contributions from patients and carers were valuable and will be included in the new guidelines on the management and treatment of IPF from the European Respiratory Society and the European Lung Foundation IPF Taskforce.

The feedback from the focus groups also played a major part in helping to shape the development of the National Patient Charter for IPF for Ireland.

ILFA would also like to thank the patients, caregivers, healthcare professionals and professional bodies who helped review the document and gave detailed feedback, helping us to improve this charter.

A film to describe the National Patient Charter for IPF is available to view on the ILFA website; **www.ilfa.ie**

Reference documents

- Position Statement from the Irish Thoracic Society on the treatment of Idiopathic Pulmonary Fibrosis.
  Available on-line at; www.irishthoracicsociety.com

- An Official ATS/ERS/JRS/ALAT Statement: Idiopathic Pulmonary Fibrosis: Evidence-based Guidelines for Diagnosis and Management by Raghu G, Collard HR, Egan JJ. American Journal of Respiratory Critical Care 2011;183(6): 788-824.

- Idiopathic pulmonary fibrosis: The diagnosis and management of suspected idiopathic pulmonary fibrosis. Guidelines from the 2013 National Institute of Health and Care Excellence (NICE), from the United Kingdom.
  Available on-line at; www.nice.org.uk/guidance

- The European IPF Patient Charter.
  Available on-line at; www.ipfcharter.org/call-to-action

- The ILFA report for the European Respiratory Society and the European Lung Foundation IPF Taskforce, 2013.

- The Irish Hospice Foundation 'Think Ahead' campaign that encourages people to plan for end of life by recording their wishes in the event of emergency, serious illness or death (2014).
  Available on-line at; www.thinkahead.ie

Need more information about IPF?

Contact ILFA to request some of our resources:

Address: ILFA, PO Box 10456, Blackrock, County Dublin.

Telephone: 086 871 5264

Email: info@ilfa.ie

Website: www.ilfa.ie

Facebook: www.facebook.com/ILFAIreland

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Plain English
Approved by NALA

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The National Patient Charter for IPF (2015)

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