

Irish Lung Fibrosis Association  
Palliative Care and Planning for the Future

World Café Meeting Report

**ILFA**

**WORLD CAFE EVENT**

**ON** *Palliative Care*

**AND** *Planning for  
the Future*

# Irish Lung Fibrosis Association

Palliative Care and Planning for the Future

ILFA World Café Meeting Report



## Introduction

In June 2018, the Irish Lung Fibrosis Association (ILFA) held its first meeting on Palliative Care and Planning for the Future. The aim of the meeting was to explore the palliative care and future care planning needs of people with pulmonary fibrosis (lung fibrosis), and to share ideas on how best to address these needs. The meeting was facilitated by Anne-Marie Russell and Tony Shone. Adopting a ‘World Café’ approach for patients, family members, healthcare professionals working in hospitals, hospices and community settings, representatives from the clergy, the Irish Hospice Foundation, and pharmaceutical and oxygen companies contributed to the discussions.

In opening the meeting, Eddie Cassidy, ILFA Chairman, explained “This important event will help ILFA understand your needs and priorities in relation to palliative care and planning for the future. We want to know what matters to you and this will help us decide on ILFA's next projects”.

The aim of this report is to share with you the information that was discussed at the meeting and steps we have taken since the event. You may also have additional thoughts that were not discussed at the meeting, but that may be helpful for ILFA, and people with pulmonary fibrosis and their family members. If so, please do not hesitate to get in touch with us.

Here are the contact details for ILFA

Irish Lung Fibrosis Association (ILFA)

P.O. Box 10456, Blackrock, Co Dublin

Email: [info@ilfa.ie](mailto:info@ilfa.ie)

Tel: 086 871 5264



Irish Lung Fibrosis Association  
[www.ilfa.ie](http://www.ilfa.ie)

## What is Palliative Care?

The World Health Organisation (WHO) describes palliative care as *“an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”*.

Palliative care focuses on providing comfort through symptom relief. The aim of palliative care is to enhance the quality of life of those living with life limiting conditions and their families. Contrary to common use of the term, palliative care is not just the care provided at the very end of life. It is appropriate at any stage for people with a life-limiting illness, from the point of diagnosis onwards, and is sometimes also described as supportive care. It uses a team approach to address the needs of patients and their families.

## The ILFA World Café Event

The ILFA meeting on palliative care and planning for the future took the form of a ‘World Café’ in which people worked in small groups to discuss a series of topics for a specified time. World Café events follow a formula that aims to maximise people’s participation and capture ideas and solutions.



Each group conversation was introduced with a focus question and the discussion was hosted by a group leader with special skills or knowledge of that field. Once the allotted time had passed, the leaders and notetakers for each topic rotated to the next group to capture their perspectives.

The topics discussed were;

- (1) Practical planning for living with Idiopathic Pulmonary Fibrosis (IPF)
- (2) Palliative care needs and management of symptoms
- (3) End of life considerations including home, hospital and hospice care at the end-of-life, and spirituality needs
- (4) Psychological needs and support for living with IPF
- (5) Acute exacerbations and transplantation concerns
- (6) Legal matters

The six leaders were;

- Irene Byrne (Respiratory Physiotherapist, Mater University Hospital)
- Lynn Fox (Respiratory Nurse Specialist, Mater University Hospital)
- Bettina Korn (End of Life Co-ordinator, St James Hospital)
- Dr Anne-Marie Doyle (Clinical Psychologist, Royal Brompton Hospital, London)
- Maria Love (Medical Social Worker, Mater University Hospital)
- Deirdre Shanagher (Development Officer, Irish Hospice Foundation)



The leaders were assisted by six note-takers; Chris Meehan, Marie Sheridan, Nicky Goodbody, Nicola Cassidy, Lindsay Brown and Marie McGowan who recorded the challenges, solutions and ideas shared by the participants.



A graphic artist captured the essence of the discussions creatively and the illustrations are included in this report.

The key findings from the World Café discussions for each topic were subsequently summarised by the leaders and note-takers and presented to the participants in 5-minute presentations. Feedback from the discussions on each of the six topics is detailed in the following pages.



**Anne-Marie Russell,  
Meeting Facilitator**

Meeting facilitator Anne-Marie Russell, Clinical Research Fellow specialising in pulmonary fibrosis at Imperial College London, explains the background to the world café event:

*“This was the first time that ILFA has brought together patients, families, healthcare professionals and other representatives to discuss palliative care. The World Café event meeting style gave people the time and space to make their individual contributions on a wide variety of topics related to palliative care. Smaller groups allowed for people to have an open and in-depth discussion on each subject, with the guidance of the group leaders. Recognising that this can be an emotional subject we made sure that patients and their families had access to appropriate support from professionals”.*

## **Meeting Findings**

### **1. Practical Planning for Living with Pulmonary Fibrosis**

**Leader: Irene Byrne, Respiratory Physiotherapist, Mater University Hospital**

*Focus question: What practical solutions would help you cope better with the challenges of living with pulmonary fibrosis?*

Irene Byrne provided feedback from the group discussions on the problems people face in living with pulmonary fibrosis, and several practical solutions were proposed.

- **Quality information and Support at the Time of Diagnosis**

Receiving a diagnosis of pulmonary fibrosis can be extremely distressing and many participants felt that patients and families don't currently receive appropriate information, support and advice at that time. There is a need for high quality information on pulmonary fibrosis to be provided at the point of diagnosis. There were suggestions that this could be in form of an information pack, through a telephone support line, sign-posting to accredited information on the internet, or via nurse specialists (as occurs in cancer care).

- **Dedicated Case Manager**

Effective management of pulmonary fibrosis involves many different members of the healthcare team. Patients felt that explaining their problems to different people at every clinic visit takes time and energy that could be better used, and that no one individual understands the full spectrum of their condition.

The concept of a dedicated patient case manager was proposed as a solution to this problem. There were also demands for a centralised patient record that can be accessed by all members of the healthcare team. As this can be a rapidly changing disease, patients should have easy access to a specialist Pulmonary Fibrosis clinic and medical and nursing specialists with expertise in pulmonary fibrosis.

*Participant quote: "We need continuity for lung fibrosis care, a fixed link to a professional who understands each patient's case"*

- **Improved Oxygen Services**

It was felt that oxygen provision is not currently a patient-centred service. Oxygen is important for patients in managing their symptoms and there should be a standardised approval process for prescriptions. Patients faced difficulties in terms of geographical area variations in approval of some devices and accessories, reimbursement of oxygen costs for non-medical card holders under the Drug Payment Scheme and obtaining more oxygen than the 'fixed package amount' regardless of their need (for example when more oxygen is needed for exercising).

- **Supports for Daily Living**

Contributors felt that there were several supports that could assist with the activities of daily living, including access to mobility parking, access to occupational therapists and help approaching employers about the possibility of reduced working hours or the practicalities of bringing oxygen to work.

There are also problems with lengthy delays in receiving grants towards home adaptations.



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## **2. Palliative Care Needs and Management of Symptoms**

**Leader: Lynn Fox, Respiratory Nurse Specialist, Mater University Hospital**

*Focus question: What ways do you think palliative care has a role in helping you the patient, carer, healthcare professional to manage IPF symptoms?*

Lynn Fox informed the meeting that participants agreed that palliative care should be a fundamental part of treatment for all people with pulmonary fibrosis. The group discussions had identified a number of ways to help achieve this:

- **Provide Information on Palliative Care Early**

Information on palliative care should be provided early, around the time of diagnosis. Discussions on the role of palliative care in the management of pulmonary fibrosis should include family members. Healthcare staff should be aware that patients and family members may have different questions, concerns and information needs in relation to palliative care, and separate discussions may need to take place.

- **Education on Palliative Care for Health Care Professionals**

Contributors felt that General Practitioners (GPs) could have a greater role in referring patients to palliative care services, and that education was needed for healthcare professionals on the role of palliative care. There should be improved communication between primary care services and palliative care, with a patient record or 'patient passport' that was accessible to all healthcare professionals involved in that patient's care.

- **Address Stigma of 'Palliative Care' Terminology**

It was identified that 'palliative care' can be a frightening term for many, as it is often associated with care provided in the final days of life. This needs to be addressed so that there is no stigma in accessing palliative care services. The focus should be that palliative care is about managing symptoms and enhancing patients' quality of life and not solely about managing the end-of-life.

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beginning

  
**COMMUNICATION**

Taking  
**JARGON**  
out of  
Conversations  


  
Palliative  
care needs  
and management  
of symptoms

  
Helping  
P.C. staff  
Understand  
**IPF**

also  
NON-healthcare  
Staff Training

  
An App  
(being  
Developed)  
**M-Power**

  
**INFORMATION**

  
Removing  
**Stigma**  
surrounding  
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 **Fundamental**  
to Treatment

### 3. End of Life Considerations

**Leader: Bettina Korn, End of Life Care Coordinator, St James Hospital**

Focus question: *What are the most important end of life care elements to support patients and families in end of life care?*

Bettina Korn informed the meeting that there was a clear theme running through all the discussions on end-of-life care: that the patient's personal choice is imperative. Personal choices and beliefs should be established and understood early on so that care can be provided in the best way for that individual. There were suggestions on how this could be achieved:

- **The Importance of Conversations on End-of-Life Care**

Every individual is different, with different wishes and for their end-of-life care, different spiritual beliefs and emotions. It is important that personal choices, such as whether they would prefer hospital, hospice or home care at the end of life, are discussed between patients, families and healthcare professionals. It was recognised that these conversations are difficult to bring up and advice and support is needed on how to create opportunities for discussion and how to guide such conversations. It is important that conversations on end of life care occur early and not left until the last moments.

Participant quotation: *"We often feel that we need space and time to open one big conversation on end of life care, but in reality, it is easier to have many ongoing conversations on the subject".*

- **Establishing personal preferences**

It is important to honour the patient's wishes, prioritise what is important to them, help them set goals and establish if they want to remain at home or if they would feel safer in a hospital setting or hospice at the end of life.

Establish a person's belief system, be sensitive to different faiths and beliefs and establish their funeral preferences and care after death.

- **Challenges at the end of life**

Challenges at end of life include fear and anxiety while pre-empting demise, and family stress and guilt. More resources (for example, homecare packages and psychological supports) are needed to facilitate palliative care services at home. It is a good idea to visit a hospice early to learn about the facilities and meet the staff to build up rapport with them. There is a delicate balance between fulfilling the wishes of the patient and their care needs, which involves knowing what the best care is. Information and education are involved in this.

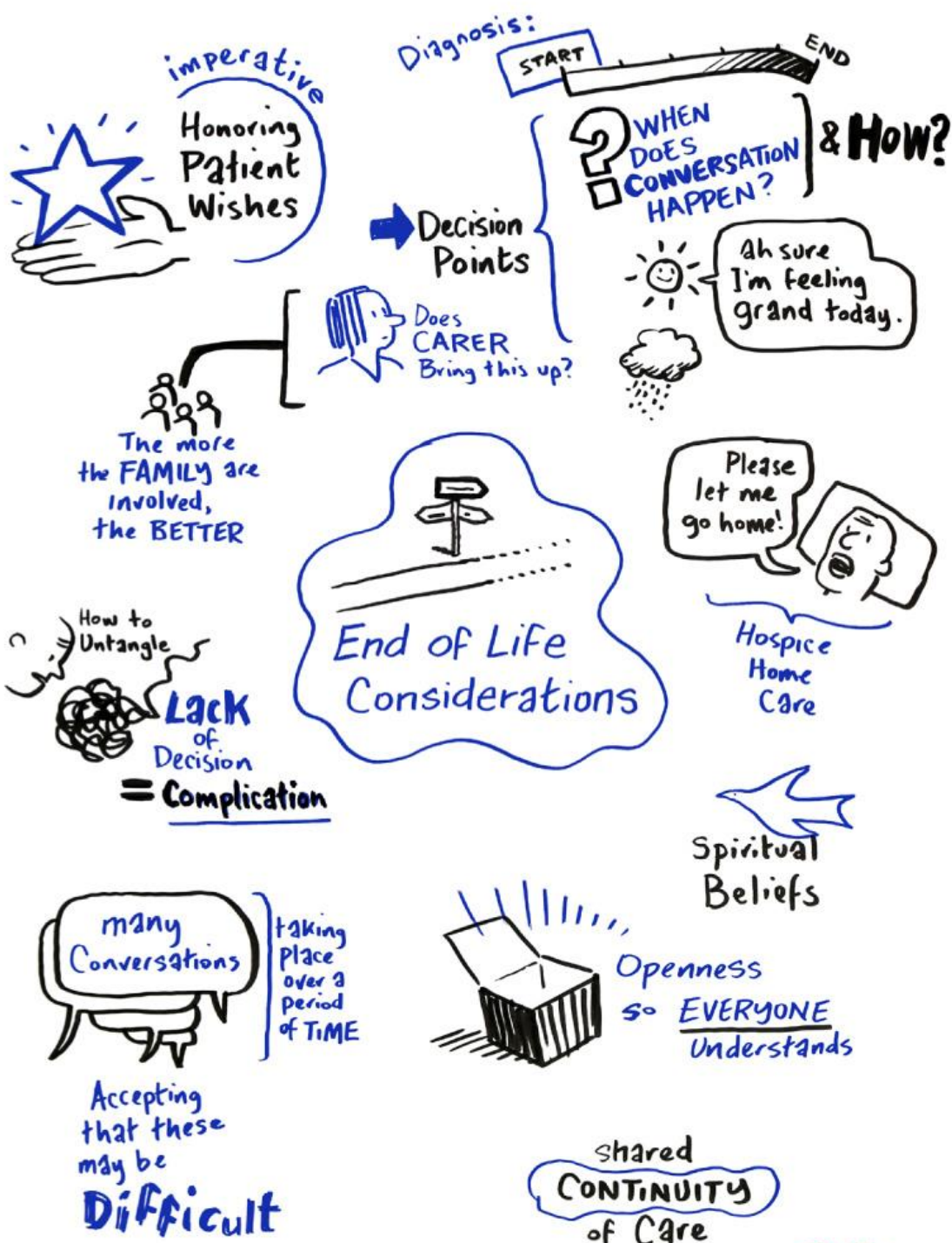
- **A Patient Charter for End of Life Care**

It was recognised that many people do not know what is available to them in considering end of life care. This makes it difficult for patients and families to make informed decisions. There is a need for patients and families to be sign-posted to factual information and resources.

The '**Think Ahead**' document from the Irish Hospice Foundation was considered a useful resource.

A patient charter was suggested to establish what represents good end of life care.

- **The National Patient Charter for Idiopathic Pulmonary Fibrosis** developed by ILFA calls for early access to palliative care supports. (See [www.ilfa.ie](http://www.ilfa.ie) for more information)
- **The People's Charter on Dying, Death and Bereavement in Ireland** developed by the Irish Hospice Foundation describes the preferences of Irish people in relation to their needs for a good death and for healthy grieving. (See [www.hospicefoundation.ie](http://www.hospicefoundation.ie) for more information)



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#### 4. Psychological Needs and Support for Living with IPF

**Leader: Dr Anne-Marie Doyle, Clinical Psychologist, Royal Brompton Hospital, London**

*Focus question: Pulmonary fibrosis often brings distress and uncertainty to people's lives. What coping mechanisms do you draw upon to manage your feelings and emotions associated with your experiences of pulmonary fibrosis?*

Dr Anne-Marie Doyle discussed the coping mechanisms that participants found useful in living with the stress of pulmonary fibrosis. The discussions identified some supports that could further reduce distress for patients and families.

- **Ways of Managing the Stress Associated with Pulmonary Fibrosis**

Many things were found to be helpful in managing stress, including taking exercise, making sure you have a good diet, keeping a sense of humour and a positive mind-set, finding joy in everyday activities and making plans for the future.

High quality support is very important for patients, particularly that provided by family and friends. Joining a patient support group such as the regional ILFA patient support groups was considered very helpful, as was taking part in a pulmonary rehabilitation programme, which as well as providing exercise also gives patients an opportunity to share their feelings with those in similar situations.

Participants felt it was important to be in control, to keep up hobbies and personal interests, be upfront and honest with family and friends, and continue to have a social life.

- **Additional Supports Needed to Help Reduce Stress**

A major issue identified was that education and support were needed for family members. Families can come under a huge amount of stress which sometimes they try and hide from their loved ones to protect them.

*Participant quotation: "Who cares for the carer and the stress that they shoulder?"*

Professional psychological supports are needed throughout the disease course: diagnosis is a particularly stressful event for patients and families, starting oxygen therapy can also be a very distressing time, as well as the end-of-life period. Patients and families should have access to psychological services and counselling to help them adjust and cope. A holistic approach to managing symptoms is needed. Carers/families may need to avail of respite care to help them manage. Healthcare staff may need emotional and psychological support when caring for patients and families.

From a practical perspective, the fact that pulmonary fibrosis is not recognised as a long-term illness and does not qualify for an automatic medical card is a major source of stress for patients and carers, as is timely access to oxygen services. Families also struggle with the practicalities of having to complete forms to access entitlements, additional financial pressures (for example, the cost of medication and oxygen) and the health difficulties of the winter months.



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## 5. Acute Exacerbations and Transplantation Concerns

**Leader: Maria Love, Senior Social Work Practitioner, Mater Hospital**

*Focus question: How can the treatment of an acute exacerbation be managed better?*

*Lung transplantation may be a treatment option for some people diagnosed with Pulmonary Fibrosis; do you have any concerns in relation to lung transplant?*

Maria Love provided feedback on the group discussions on ways acute exacerbations of pulmonary fibrosis may be better managed, and shared details of the conversations on lung transplantation.

### **Managing Acute Exacerbations**

#### **What is an Acute Exacerbation?**

The medical definition of an acute exacerbation of IPF is “an acute, clinically significant respiratory deterioration characterised by evidence of new widespread alveolar abnormality.”

If you experience a rapid deterioration in your symptoms, such as breathlessness, you should seek medical help urgently.

- **Education**

There were several questions raised on acute exacerbations; what is it – is there a standard definition of what an exacerbation is? How to recognise an exacerbation? How can we avoid one in the first place? Where should you go if you have an exacerbation; to your GP, your respiratory clinic or to a hospital emergency department? These questions identified that education on pulmonary fibrosis and exacerbations, and a defined care pathway is needed for patients, families and healthcare professionals. It is important for patients and families to know what to do when someone becomes unwell.

- **Shared Access to a Health Passport**

A 'health passport' which provides details of a patient's conditions, medications, hospitalisations, etc., to any healthcare professional treating that patient would be very useful in improving the management of exacerbations. This would be especially useful in the setting of a hospital emergency department where staff may not be familiar with pulmonary fibrosis.

- **Appropriately Resourced Services**

Adequately resourced healthcare services and integrated care between the community and hospital are required for the better management of acute exacerbations. Access to respiratory nurses and other healthcare professionals, for example via telephone or rapid access clinics would be extremely useful both for treatment and psychological support. Having a care pathway from the emergency department to hospital wards and out-patient clinics was also discussed as being useful for patients and families, in order to effectively diagnose and treat acute exacerbations.

### **Transplantation**

There is a need for greater awareness and education for healthcare professionals and those diagnosed with pulmonary fibrosis on lung transplantation as a treatment option, the assessment process involved and eligibility criteria. Lack of knowledge about lung transplant, how and when to refer someone for transplant assessment, and the timing and criteria for referral for assessment were discussed.

There are limited numbers of beds and human resources available for transplant assessment and transplant care at the National Lung Transplant Centre at the Mater Hospital. As a result of this, the group felt that assessment was a lengthy process and that there were inequities in how quickly some assessment tests were completed in private hospitals (if someone had private healthcare insurance), versus the time it took for tests to be completed in the public healthcare system.

As many people considered transplant a daunting process, a mentoring system (a 'Buddy' approach), whereby support and information could be provided by patients and families who have gone through lung transplantation to those considering transplantation was suggested.

Similarly, information on referral criteria for transplant assessment and transplantation would be helpful for patients, families and healthcare professionals.



## 6. Legal Matters

**Leader: Deirdre Shanagher, Development Officer, Irish Hospice Foundation**

*Focus question: What legal matters are important to you to help you make good decisions and manage a life-limiting condition such as Pulmonary Fibrosis? Have you made or considered making a will or an advance healthcare directive?*

Deirdre Shanagher presented the feedback from the group discussion on legal matters for end-of-life care. Once again, the importance of open, early and on-going conversations on end of life and planning were considered important. There were four areas considered:

- **Making a Will**

This was considered to be very important, and people found that the thought of making a will is much harder than actually doing it. Advice is needed on the practicalities of making a will, for example how to do it, how much it might cost, how can a will be changed?

- **Advanced Healthcare Directives (Living Wills)**

It was felt that advanced healthcare care directives or living wills are very useful and provided clarity for both healthcare professionals and families in understanding and honouring patients wishes.

## What is an Advanced Healthcare Directive or Living Will?

An advanced healthcare directive, sometimes known as a 'living will', is a statement about the type and extent of medical or surgical treatment you do want in future, on the assumption that you will not be able to make that decision at the relevant time.

According to the Irish Hospice Foundation's 'Think Ahead' document an Advance Healthcare Directive is an expression made by a person who has reached the age of 18 years who has capacity in writing (to include voice, video recording and speech recognition technologies) of their will and preferences concerning specific treatment decisions that may arise if he or she subsequently lacks capacity. An Advance Healthcare Directive is legally binding (therefore certain formalities must be followed) when a person writes down what treatments they would refuse in the future and the circumstances in which the refusal is intended to apply. The Assisted Decision Making (Capacity) Act (2015) provides that a request for specific treatment is not legally binding but should be followed if relevant to the medical condition for which treatment is required. Codes of practice are being developed to indicate the formalities required to comply with the provisions of the ADMC Act (2015).

Please consult the Irish Hospice Foundation's 'Think Ahead' programme which provides a guide to members of the public to help you discuss and record your preferences in the event of an emergency, serious illness or death.

See [www.hospicefoundation.ie/programmes/public-awareness/think-ahead/](http://www.hospicefoundation.ie/programmes/public-awareness/think-ahead/)

Advanced healthcare directives can help patients feel in control and are useful for family members and healthcare staff. They can take the pressure off family members when important medical decisions must be made. There is need for awareness raising and training on advanced healthcare directives for patients, family members and healthcare professionals. Multiple conversations should be had with family members and healthcare staff to ensure the patient's wishes are known. Advanced care directives should be discussed and taken care of before a health crisis occurs.

- **Enduring Power of Attorney**

## What is an Enduring Power of Attorney?

Power of attorney is a legal mechanism that can be set up by a person during their life when they are in good mental health. It allows another specially appointed person (the attorney) to take actions on their behalf if they are absent, abroad or incapacitated through illness. An enduring power of attorney also allows the attorney to make personal care decisions on the donor's behalf once they are no longer fully mentally capable of taking decisions themselves.

Reference: [www.citizensinformation.ie](http://www.citizensinformation.ie)

Setting up an enduring power of attorney was considered to be a good idea. It can give peace of mind and relief to a patient, and can help families with decision making, especially as pulmonary fibrosis is an unpredictable condition and a person's health status can change suddenly. It can be a complicated and lengthy procedure to set up and proper consideration needs to be given on whom to select to act as your representative.

- **Critical Illness Cover**

Some participants have had difficulty in getting payments from insurance providers when they claimed under their critical illness scheme. Advocacy is needed to get Pulmonary Fibrosis recognised as a critical illness by insurance companies.



## Next Steps

After the World Café event, we conducted in depth qualitative interviews with three patients and their spouse or a family member to explore in greater depth the impact that the meeting had. Three 'pairs' were interviewed by Anne-Marie Russell. The key areas explored were recognising and managing exacerbations – managing the transition to oxygen therapy and the process of increasing oxygen needs; accessing palliative care; preparing for end of life, and the great added value of patient support groups.

The World Café event organisers and group leaders had a follow up meeting in August 2018 to discuss the findings of the meeting and the feedback and evaluation from meeting participants, and to make additional plans for the future. The feedback from the participants was very positive and informative and was presented at the Irish Thoracic Society meeting in November 2018.

As a result of these activities, ILFA now has a more complete understanding of the issues and concerns of people with pulmonary fibrosis and their families with regard to palliative care and advance care planning. We will now aim to deliver a series of awareness, education and advocacy, and lobbying initiatives to help address these issues.

ILFA will hold a patient information day in Dublin on Saturday 6<sup>th</sup> April 2019 that is dedicated to palliative care and planning for the future. The event is open to patients, family members and healthcare professionals who wish to learn more about palliative care and planning for the future with pulmonary fibrosis. The event will be chaired by Anne-Marie Russell and speakers will include healthcare professionals with specific expertise in the field.



## **Acknowledgements**

The ILFA Committee would like to thank everyone who attended the World Café event - your contributions and willingness to share your personal experiences and perspectives made the meeting so valuable.

We would also like to extend our sincere thanks and appreciation to everyone involved in developing, organising, and delivering the meeting for generously sharing their knowledge, skills and time. We are especially grateful to Tony Shone (Invisio Ltd.) and Anne-Marie Russell for their generosity, leadership and expertise in delivering the World Café event. Sincere thanks to the six leaders and note-takers for their enthusiasm, attention to detail and willingness to take part, to Carol Keely for legal advice and to Philip Barrett for his great artwork that captured the main themes and essence of the World Café event.

## **Feedback received from some of the participants at the event**

- Thank you for all the hard work that went into arranging today - it was absolutely marvellous.
- Informative, welcoming, supportive. It helped me to open my thoughts to areas I hadn't thought about.
- Very helpful, friendly, informative.
- A very powerful day, run very professionally, organised extremely well. Well done to all concerned and I am personally appreciative of all that is done on our behalf.
- Very enjoyable, informative, very relaxed open atmosphere.
- Whilst a difficult subject it was uplifting in a sense to know we're all in the same boat.
- Facilitators were excellent at distilling a huge amount of information. Great to see the support patients/families have for each other and others in similar situations.
- Great event. Gives people a chance to talk.
- It was informative, well organised, helpful.
- Thank you to all involved in putting this day together.
- It was fantastic.

# Thank you!



Irish Lung Fibrosis Association

Postal Address: PO Box 10456, Blackrock, County Dublin

Website: [www.ilfa.ie](http://www.ilfa.ie)

Enquiries: 086 871 5264

Registered Address: Lavery House, Earlsfort Terrace, Dublin 2

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