NHS
Wrightington, Wigan and Leigh Teaching Hospitals
NHS Foundation Trust

Supporting Carers of Patients with Interstitial Lung Disease (ILD)

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Patient Information

Respiratory Service

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Introduction

Interstitial Lung Disease (ILD) is a term given to a group of respiratory diseases affecting the tissue (the interstitium) of the lung. In this condition the air sacs or alveoli become inflamed, scarred and thickened.

When your loved one is diagnosed with an ILD, prognosis and management can differ significantly.

Sometimes medication can be offered, other times, we monitor the progress of the disease with a pulmonary function test (PFT). However, we will always strive to offer advice on the symptoms of the disease, and suggest a referral to our supportive and palliative care team.

As a loved one of someone with an ILD, we acknowledge that the strain of the disease doesn't just affect the patient, but you as well.

Activities of daily living (ADL) can become challenging for the patient due to the symptoms of the disease, such as:

- Shortness of breath (SOB)
- Cough
- Increased tiredness/fatigue
- Lack of appetite/change in sensation of taste

- Mood changes

This can lead to physical and psychological strain to you as well.

The hope is that this leaflet will give you a better understanding of the disease, and will help you to recognise, at an early stage, any changes that could be a sign of deterioriation; it will give you advice on when to ask for help but also information on support that is available within the community.

This leaflet will hopefully give you clarity, and will support you as a carer/loved one/friend or family member to someone with an ILD.

Overview

Anyone can develop an ILD. In the case of over 75% of the patients we care for, there is no clear reason for the illness (this is known as idiopathic). However, many things can increase the risk of development, including:

- Smoking related
- Breathing in certain inhalants (occupational and environmental exposure)
- Taking certain medication/antibiotics/chemotherapy/radiotherapy

- A preexisting autoimmune disease (CTD) such as rheumatoid arthritis
- Genetic conditions
- Having an infection/inflammatory disease (COVID/ Pneumonia)

Potential symptoms of ILD

Prior to diagnosis, a person may complain of:

- A long-term (over 2 months) dry cough that doesn't produce sputum
- SOB that is reducing how far they can walk
- Difficulty due to SOB with activities of daily living, such as washing/dressing
- Nails that look 'bubble like' clubbed (can be a sign of ILD, though there are also other causes for this)
- Low oxygen levels on walking/exercising

After diagnosis

- Discussion and/or referral for consideration of a type of medication that slows down the disease process (antifibrotics)
- PFT (pulmonary function test) monitoring (patient dependent)

- Blood monitoring when on the antifibrotics (patient dependent)
- Referral to our supportive and palliative care team for physical and psychological support of the disease

When to ask for help

- A cough that has returned after change of medication ie stopping of steriods
- Feeling like they cannot walk as far as they could do previously.
- Symptoms that have started after medication; for example, antifibrotics can cause diarrohea and vomiting.
- More short of breath than usually meaning they can’t walk as far as they previously could (with in a short period of time)

When to seek medical help via GP /111 or A&E

- Struggling to breathe and cannot talk in their ‘normal’ breath.
- Looking blue (cyanosed) to nails, lips or nose.
- More drowsy than usual.
- New confusion.
- Chest pain/tightness that is new

We have one ‘Ask’

If your loved one is admitted to hospital, we would really like to know. If possible, we would ask that you call one of the numbers on this leaflet and leave us a message.The aim of this is to be a ‘friendly face’ to your loved one, to give help where possible with management planning, and to support discharge/admission if appropriate at the earliest opportunity.

Abbreviations you may see in letters

ILD – Interstitial lung disease

PFT - pulmonary function test

CTD – connective tissue disease

FVC – forced vital capacity

DLCO – lung diffusion

ADL – activities of daily living

Clinicians you may see in clinic and contact details

01942 822977 (answer machine only)

Dr Ashish (Respiratory consultant)

Dr Narasimhaiah (Respiratory Consultant)

Heidi Prior (Advanced Nurse Practitioner)

Sandra Dermott (ILD Nurse)

Julie Kelley (ILD Nurse)

These members of staff will help you with any questions in relation to the disease and the process, also with the next PFT date, and with a brief explanation of test results.

Supportive and Palliative care team

01942 822008

Sarah Simm (palliative care specialist nurse)

Kate Ramsden (palliative care specialist nurse)

Jemma Whittle (support worker)

Symptom relief for the disease (medication/psychological)

Oxygen team

01942 778626

Baywater (oxygen) – 0800 373580 can provide equipment advice

Kathryn Dalton (Oxygen Sister)

Sarah Smith (Oxygen Sister)

Advice when on long term oxygen.

Helpful webpages

Action for Pulmonary fibrosis -

www.actionpf.org

Community link worker –

www.wigan.gov.uk/Resident/Health-Social-Care/Adults/fit-and-well/Community-link-workers.aspx

Equipment advice –

www.wigan.gov.uk/Resident/Health-Social-Care/Adults/Making-life-easier-at-home/index.aspx

Wigan and Leigh Carers Centre

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Hindley

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