

INTERSTITIAL LUNG DISEASES – THE FIRST STEPS at Heart of England NHS Trust:-

Interstitial lung diseases are complicated, difficult and relatively rare. There are many of them with different abbreviations. Some get better when you take the cause away. Some get better with relatively simple treatment. Some require more complicated treatment and some do their own thing more or less whatever you do.

The first steps are to make a definite diagnosis of which one you have. This information sheet will describe the steps involved and help you may receive.

Interstitial pulmonary fibrosis (IPF) is a blanket term which covers all of these diseases.

We find out whether you have an interstitial lung disease from the chest x-ray and from your breathing tests. This however very rarely tells us which one you have. You should have had both of these by the time that you receive this information.

The next main steps are:-

- 1 To find possible causes
- 2 To do a high resolution CT scan of your lungs
- 3 To do a bronchoscopy

After these 3 steps, we can make a diagnosis in about two thirds of you. For the remainder, making a definite diagnosis requires a biopsy of the lung.

A SEARCH FOR A CAUSE:-

Interstitial lung diseases may be caused by things you breath in and become allergic to (for instance birds, moulds, metal working fluid, drugs used to treat urine infections such as nitrofurantoin, drugs used to treat heart disease such as amiodarone, drugs used to treat rheumatic conditions such as methotrexate as well as wide range of occupational exposures, particularly asbestos, silica, metals, wood dusts etc. You will be asked to give a full history of your jobs and exposures and drugs that you have received. Sometimes, taking the cause away is enough to cure the disease.

The CT scan will take place at Heartlands Hospital, Solihull Hospital or Good Hope Hospital. It is a simple test; you have to hold your breath for about 20 seconds. It is very important to take a deep breath in and hold your breath. If you have problems with this you should tell the staff doing the test beforehand. You have to lie down for this test. It involves no injections or anything painful or unpleasant. The whole thing takes about 10 minutes or less. There is an alternative technique of doing the CT scan done slice by slice which takes a bit longer and where you do not have to hold your breath for so long.

BRONCHOSCOPY:-

It may be possible to omit this test if allergy, infection or some rarer causes of lung fibrosis can be confidently excluded. The main value of the bronchoscopy is to wash some fluid in and out of your lungs to get some samples from the remote part of the lungs (the alveoli/air sacs). By looking at the cells that we get out under the microscope, you can have a good idea as to whether this is at least predominantly due to infection, predominantly due to allergy or something else. You need to have nothing to eat or drink for 4 hours beforehand. You will be sedated for the investigation and given local anaesthetic and you will need somebody to take you home 2 -3 hours after you have had the test.

THE NEXT STAGE – THE INTERSTITIAL LUNG DISEASE BOARD:-

If the above tests confirm that you have an interstitial lung disease, your case will be discussed at a multidisciplinary meeting where we will review your x-rays, any pathology specimens available and the results of your blood tests. The team will include clinical nurse specialists, radiologists (the doctors who look at X-rays), pathologists (the doctors who look at the cells and bits of lung tissue) and chest physicians; some of these may come from other trusts. The main aim of the meeting is to decide whether we can make a diagnosis based on the material we have already or whether a formal lung biopsy is needed. The MDT report will list those present at the meeting.

You will be seen in the clinic after this meeting to discuss the results with you.

FORMAL LUNG BIOPSY:-

This requires an anaesthetic, an inpatient stay of usually 2 – 3 days and is done with keyhole surgery. If you have a biopsy of this sort your results will be discussed again at the Interstitial Lung Disease Board

HELP AND SUPPORT:-

To help you through this process, you will be helped by a Specialist Interstitial Lung Disease Nurse.

Geraldine Bale sees patients from the Birmingham Chest Clinic, Heartlands and Solihull Hospitals, she can be contacted by telephone (0121 424 0745). You can leave a message for her and she will phone you back. She is available on Mondays and Tuesdays but answers the phone on other days. She may additionally phone you at home to offer support.

Katie Neighbour sees patients from Good Hope Hospital, she can be contacted by telephone (0121 424 7503).